# Examining First Nations Dementia Perspectives and Wholistic Relational Supports for Culturally Safe Risk Reduction, Assessment, and Post-Diagnosis Care in Northwestern Ontario

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*For my Opa*

*(December 14, 1933 – May 25, 2025)*

*I'll be missing you.*

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**Abstract**

In Canada, the incidence of dementia among First Nations, Métis, and Inuit (FNMI) populations is projected to increase by 273% by 2050, in comparison to 187% among non-FNMI populations. While Canada's dementia strategy emphasizes improving risk reduction, assessment, and post-diagnosis care, such efforts must be culturally safe. Approaches must respect and reflect FNMI identities, beliefs, knowledge systems, and practices, and support community development and self-determination. Despite this, there is little published research about FNMI cultural perspectives of dementia, including the meaning of symptoms, risk reduction, assessment, and post-diagnosis care. There is also limited research documenting the supports within communities that could support collaborative and self-determined dementia initiatives. This community-based project, in partnership with a regional First Nations-led organization in Northwestern Ontario, aimed to examine the meaning of dementia symptoms, risk reduction, assessment, and post-diagnosis care among FNMI people living in Northwestern Ontario, and the existing supports that may facilitate dementia efforts in this region. Guided by a Nishnaabe research paradigm and a community advisory committee, I conducted knowledge-gathering circles and semi-structured one-on-one and two-on-one in-person and virtual interviews, using a modified photovoice approach, with predominantly First Nation adults ($n$ = 42; $M_{age}$ = 59, $SD$ = 16.02) residing in rural and urban communities in Northwestern Ontario. Stories and visual images were analyzed using reflexive thematic analysis. Qualitative analysis revealed 14 themes related to the meaning of dementia symptoms, risk factors and reduction strategies, wholistic assessment, post-diagnosis care, and 31 individual, interpersonal, and community-level relational supports. This research will enhance dementia care in Northwestern Ontario and guide future studies in the region, with potential national and international

relevance. It also supports the goals of Canada's dementia strategy by advancing culturally safe approaches to dementia care.

*Keywords:* First Nations health, Indigenous health, dementia, Alzheimer's disease, asset-mapping

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**Examining First Nations Dementia Perspectives and Wholistic Relational Supports for Culturally Safe Risk Reduction, Assessment, and Post-Diagnosis Care in Northwestern Ontario**

The incidence and prevalence of dementia are rising in Canada and pose substantial challenges to public health and quality of life (Alzheimer's Society of Canada, 2024). Dementia is a clinical syndrome caused by neurodegeneration due to several types of pathologies (e.g., Alzheimer's Disease), primarily characterized by a progressive decline in cognitive abilities and behavioural capacities that interfere with the ability to engage in activities of daily living (e.g., Grand et al., 2011). In Canada, the prevalence and incidence of dementia are higher among Indigenous Peoples[1] when compared to non-Indigenous people (Alzheimer's Society of Canada, 2024). Approaches to addressing the key pillars of Canada's dementia strategy (Public Health Agency of Canada, 2019) (e.g., risk reduction, assessment, and post-diagnosis care) within Indigenous populations must be culturally safe. In other words, approaches must respect, recognize, and reflect the needs, unique identities, beliefs, knowledge, and practices of Indigenous Peoples in Canada, and reflect a collaborative approach that fosters community development and self-determination (Jacklin & Walker, 2020; Menzies et al., 2020; Smye et al., 2010). Despite evidence suggesting a high prevalence of dementia and limited culturally safe dementia services for Indigenous Peoples in Northwestern Ontario (Gusul, 2013), Indigenous perspectives on dementia and existing strengths, resources, and capacities (i.e., relational

[1] There is no universally accepted definition of Indigenous Peoples. However, the United Nations defines Indigenous Peoples as "those who, by self-identification, have a historical continuity with a given region prior to colonization and strong link to their lands and maintain distinct languages, cultures, beliefs, and knowledge systems from the mainstream or dominant society" (Nguyen et al., 2023, p. 1). There is also considerable diversity between Indigenous Nations globally. However, the limited research on dementia within this population warrants drawing on global Indigenous perspectives. In this thesis proposal, I will utilize nation-specific language (e.g., First Nations, Nishinaabe) when the literature supports this use and Indigenous when the literature speaks to multiple international Indigenous Nations.

supports) that may facilitate care in this region remain unexamined. I seek to address this gap in the literature and community-identified need by examining the cultural meaning of dementia symptoms, risk reduction, assessment, and post-diagnosis care among Indigenous Peoples living in Northwestern Ontario and the existing relational supports that may facilitate culturally safe dementia care in this region.

**Self-location**

As researchers, we are intrinsically intertwined with our research through the questions we ask, how we ask them, the teams we assemble, the people we recruit, and the meaning we make from the stories shared with us. I do not believe we can write ourselves out or be entirely neutral or objective in our research, and I know the potential misinterpretations and harm that can occur when we believe we can (e.g., Absolon & Willet, 2004; Harding, 1992). Instead, our positionality, or all the stories, relationships, and experiences that make us who we are, can negatively or positively influence our research. Kovach (2009) shares that "in Indigenous contexts, location does matter (…) people want to know who you are, what you are doing, and why" (p. 71). Self-location implies clarifying one's worldview and reflects congruency with a relational knowledge system that suggests we can only interpret the world from our place of experience (Kovach, 2009; Wilson, 2008). Accordingly, I begin this thesis by locating myself.

I am a Michi Saagiig[2] Nishnaabe[3] kwe with Dutch, German, Irish, and Danish heritage, and a band member of the Mississauga's (Michi Saagiig) of the Credit First Nation. I belong to the King family and the Migizi Dodem (Eagle Clan). This means that my clan's responsibilities are in education and sharing knowledge. I did not grow up on reserve, as I grew up without First Nations status due to the gender discrimination in the Indian Act. With corrective legislation (Assembly of First Nations, 2020), my family and I have regained status, been remembered and re-membered to our community, and developed ties with our family members on reserve. I am hesitant to say that I did not grow up in my culture, however, as I am continuously challenging myself as to what I and others mean by Indigenous, Nishnaabe, or Michi Saagiig culture. When I reflect on my childhood, building tipis in the backyard and making dreamcatchers is not what strikes me as what it means to be Michi Saagiig. Instead, it is the relentless pursuit of kindness, generosity, respect, courage, honesty, autonomy, love, altruism, and care that my Michi Saagiig father and grandmother demonstrated throughout my entire life. It was not until I began to understand our culture that I could see that these were our values passed on, perhaps implicitly,

[2] While the *Publication Manual of the American Psychological Association (7th edition)* (American Psychological Association, 2019) requires authors to italicize words from other languages, I have intentionally chosen not to italicize Anishinaabemowin in this thesis, out of respect for its status as the original language of the territory on which this research was conducted.

[3] Nishnaabe (pl. Nishnaabeg) may be spelt Anishinaabe, Anishinabe, Anichinape, or Neshnabe, among other regional-based spellings. The diverse spellings reflect regional dialects. Nishnaabe refers to a group of culturally related First Nations located within the Great Lakes areas of Canada and includes the Ojibwe, Chippewa, Odawa, Potawatomi, Algonquin, Saulteaux, Nipissing, and Mississauga (Michi Saagig).

across generations. These are the values that I continuously seek to cultivate within my life and what I believe is part of what it fundamentally means to be Michi Saagiig.

When I moved to Thunder Bay, Ontario, for my Master's degree, I sought opportunities to engage with the Nishnaabeg community. I believe this is part of my responsibility as a guest on this territory and as a member of the Nishnaabe Nation. Shortly after, I attended a full moon ceremony at a local Indigenous-led women's organization in the region. As the ceremony started, the Elder[4] mentioned that the empty chairs in the room were filled with our ancestors who were visiting and supporting us. I felt a lump in my throat, given that my Nishnaabe great-grandmother and grandmother did not have the opportunity to connect with their culture and community. My great-grandmother, Violet King, was involuntarily disenfranchised from her Miichi Sagiig identity and community when she married and was no longer permitted to live on the reserve. I am told she never spoke about being Miichi Saagiig. My grandmother, Edith Skov, experienced many adversities in her life. She suffered from chronic illness, including diabetes, Parkinson's, and cognitive impairment at the end of her life, and passed away in her 60s. These were the women whose culture, identity, stories, health, and intergenerational relationships were stolen from them, yet as I looked at the empty chair, they sat with me as I reclaimed what they could not.

When our community members' lives are impacted or cut short due to chronic illness, such as dementia, our families and communities feel the impacts. Stories are not shared, knowledge is not transferred, and roles and responsibilities are left unclaimed. This has a ripple effect on the

[4] The word elder carries a unique meaning in many Indigenous communities. For instance, a community typically recognizes an Elder as holding community knowledge and living one's life according to cultural values and can be of any age. In contrast, elder, commonly used outside of Indigenous communities, describes individuals aged 65 and over. In the present study, I will utilize the Elder when referring to the former and the elder when referring to the latter.

next generation, whereby poor health risks are what is transferred. Accordingly, my interest in culture, community, and health within Nishnaabeg is gendered and personal.

As Nishnaabeg, we are encouraged to use our gifts to contribute meaningfully to the well-being of our communities and Nations. Many years of colonization, often uniquely experienced through gender, have limited our abilities to do so. Biskaabiiyang describes a process of returning to ourselves (Simpson, 2017). Absolon (2011) states that Indigenous research is "a healing movement of being reconnected and remembered from the dismemberment and disconnections created by colonial policy" (p. 69). Indeed, research has been a method of biskaabiiyang, whereby I have learned to use my gifts and interests to connect and contribute meaningfully to the community while allowing our Miichi Sagiig and Nishnaabe values to guide my work and life so that I may wake up and live Nishnaabeg life each day (Simpson, 2017).

My interest and privileged opportunities to engage in First Nation dementia research have been nurtured and guided by many experiences and people. My first encounter with people living with dementia, and dementia as a syndrome, was meeting and visiting my prior partner's father, who was diagnosed with dementia after a stroke. I was struck by the permanent, far-reaching, and life-altering impact that this syndrome had, not only on his father but the entire family, and how this was further complicated by living in a rural and remote community. In my second year of my undergraduate degree at the University of Victoria, I found myself drawn to learning more about Alzheimer's disease and dementia in a neuropsychology course. I was especially interested in learning about the factors that increase the risk of the disease and the underlying causal biological mechanisms. In the next semester, I learned that dementia was more prevalent among First Nations Peoples than non-Indigenous people in Canada. This intrigued me, and I was driven to explore this further. Through my journey in community-based HIV/AIDS health research, I

met my supervisor, Dr. Christopher Mushquash, and second reader, Dr. Jennifer Walker, who have supported my intrinsic motivation to learn more and meaningfully contribute to dementia research with and for First Nation communities. The frequent serendipitous experiences that have led me to engage in this research have reinforced my belief and confidence in the Creator's vision and journey for us, and that all we often have to do is be with community, listen to spirit, find and use our gifts, and trust.

## Alzheimer's Disease and Related Dementias: Etiology, Risk Factors and Clinical Features

Dementia is a syndrome characterized by symptoms caused by underlying brain pathologies that reduce the ability to engage in activities of daily living (e.g., bathing, dressing, and toileting; e.g., Alzheimer's Society of Canada, 2024). Progressive, age-related, and chronic types of dementia include Alzheimer's dementia, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and mixed dementia (i.e., Alzheimer's dementia and related dementias; e.g., Alzheimer's Society of Canada, 2024; Grand et al., 2011). In Canada, Alzheimer's and vascular dementia are the most common types and account for up to two-thirds of cases (e.g., Grand et al., 2011). The pathogenesis of Alzheimer's disease, the cause of Alzheimer's dementia, includes the formation and gradual accumulation of abnormal proteins and inflammation, which leads to neurodegeneration and symptoms (e.g., Chen et al., 2009; Jin et al., 2015). In contrast, several pathologies, including stroke, narrowed blood vessels, and other cerebrovascular diseases, are associated with vascular dementia (e.g., Grand et al., 2011). In most cases, Alzheimer's dementia and related dementias are related to a combination of genetic and cumulative lifestyle and environmental factors (e.g., Livingston et al., 2020; 2024). Non-modifiable risk factors include older age, female sex, and genetics (e.g., Baumgart et al., 2015; Barnes & Yaffe, 2011), whereas potentially modifiable risk factors include environmental and lifestyle factors that influence risk across the lifespan (e.g., Livingston et al., 2020; 2024).

Alzheimer's dementia and related dementias vary in disease progression, course, and symptoms. Alzheimer's dementia, Lewy body dementia, and frontotemporal dementia typically have an insidious and gradual onset, whereas vascular dementia can have either a sudden or gradual onset (e.g., Grand et al., 2011). Dementia may be preceded by a prodromal stage, commonly referred to as mild cognitive impairment, or subjective cognitive decline undetectable by cognitive assessments (e.g., Grand et al., 2011; Jessen et al., 2014; Sperling et al., 2011). People living with dementia typically present with neuropsychological symptoms, including memory impairments (e.g., declarative and procedural memory), aphasias (e.g., receptive or expressive language difficulties), apraxia (i.e., difficulty with carrying out coordinated movements), agnosia (i.e., difficulties recognizing objects, environments, or self), and executive functioning difficulties (e.g., self-regulation, planning, and emotion regulation; Grand et al., 2011). Further, people living with dementia often present with progressive behavioural and psychological symptoms of dementia (e.g., depression, personality changes, hallucinations, apathy, paranoid ideation, and delusions) and difficulties in activities of daily living, such as personal hygiene (Grand et al., 2011).

**Dementia Risk Reduction, Assessment, and Post-Diagnosis Care**

Canada's dementia strategy (i.e., *A Dementia Strategy for Canada: Together We Aspire)* emphasizes risk reduction, assessment, and post-diagnosis care (Public Health Agency of Canada, 2019). Risk reduction focuses on efforts to reduce the risk of the onset of dementia by targeting the modifiable risk factors of dementia. Livingston et al. (2024) identified 14 modifiable risk factors that are associated with the incidence of dementia, including lower early life education, untreated hearing and vision loss, traumatic brain injury, high LDL cholesterol, hypertension, excessive alcohol consumption, obesity, tobacco smoking, untreated depression, social isolation, physical inactivity, exposure to air pollution, and type 2 diabetes, which

accumulate risk across the lifespan (Livingston et al., 2024). Childhood adversity, unskilled work history, hyperlipidemia, low body weight, poor mobility, and incontinence may also increase the risk of dementia (Nguyen et al., 2023). Given that modifiable risk factors may reduce the risk or delay up to 45% of Alzheimer's dementia and related dementias, efforts have emphasized reducing risk by maintaining appropriate blood pressure levels, reducing exposure to air pollution, detecting and treating high HDL cholesterol, screening and treating vision and hearing loss, preventing head injuries and type 2 diabetes, reducing alcohol use, reducing or discontinuing tobacco smoking, engaging in regular vigorous physical activity (e.g., aerobic exercise), and supporting early-life education (Livingston et al., 2024). Interventions targeting modifiable risk factors (e.g., exercise) with at-risk participants have improved global cognition, executive functioning, and processing speed compared to an active control group of general health advice (e.g., Ngandu et al., 2015), providing support for their effectiveness in reducing the risk of dementia.

Assessing dementia symptoms facilitates risk reduction (e.g., risk assessment), diagnosis, treatment planning, and evaluation of symptom change. Assessment is a multi-step process and includes an iterative process of ruling in and out causes of memory impairment (e.g., potentially reversible causes of cognitive impairment, such as vitamin deficiencies) and assessing the history of symptom onset, ability to engage in activities of daily living, medical history (e.g., identifying risk factors), family medical history, and neuropsychological (e.g., executive functioning) and neuropsychiatric symptoms (e.g., mood) (e.g., Medina & Banks, 2019). While symptoms are often initially identified by primary care practitioners (e.g., Bello-Haas et al., 2014), formal assessment is typically completed by a healthcare team of specialists (e.g., neuropsychologists and geriatricians) using neuropsychological tests, laboratory tests (e.g., blood work), genetic

testing, and neuroimaging (e.g., magnetic resonance imaging) (Ismail et al., 2020; Turner et al., 2020).

Post-diagnosis care for people living with dementia may include assessing symptom progression, slowing the progression of symptoms (e.g., through pharmacotherapy), support programs for people living with dementia and informal care partners (e.g., support groups, psychoeducation, and psychosocial interventions), and access to healthcare services (e.g., respite and long-term care) (Ismail et al., 2020).

**Dementia in First Nations, Métis, and Inuit Communities in Canada**

First Nations, Métis, and Inuit (FNMI) are the recognized Indigenous Peoples in Canada, characterized by vast cultural and historical diversity. For example, over 630 First Nation communities in Canada represent 50 distinct nations and 50 language groups (Government of Canada, 2024). While there is a projected increase of 187% of non-FNMI people in Canada living with dementia by 2050, there is a projected increase of 273% among FNMI people (Alzheimer's Society of Canada, 2024). Alzheimer's dementia and related dementias may also be more prevalent among First Nations than Inuit and Métis (Jacklin et al., 2012). Compared to non-FNMI people, dementia within FNMI populations occurs at a younger age (Hendrie et al., 1993; Jacklin et al., 2012), is more common in males than females, and is more heavily influenced by potentially modifiable risk factors compared to non-FNMI people (Macdonald et al., 2015). These variations highlight the need for dementia research with and for FNMI communities.

The social determinants of health help to explain the higher incidence and prevalence of dementia among FNMI communities (Henderson et al., 2019; see Henderson et al., 2024 for a review). According to the World Health Organization (WHO), social determinants of health are "conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life (…) including economic policies and systems,

development agendas, social norms, social policies and political systems" (World Health Organization, 2021, para. 1). For FNMI Peoples, colonization reflects a historic and ongoing social determinant of health, involving geographic incursion, socio-cultural dislocation, economic dispossession, political control, systemic racism, and the provision of low-level health services (e.g., Kelm, 1999). Colonization is reflected in the creation of the reserve system, unjust laws, historic Residential Schools, contemporary child welfare systems, violent dispossession and displacement of FNMI people from their territories (including pollution of lands and waters), involuntary disenfranchisement (e.g., through gender discrimination in the Indian Act; e.g., Cannon, 2006), disruption of cultural continuity and identity, White supremacy, reduced access to economic opportunities and resources, inadequate services and infrastructure on reserves, and racism (e.g., Adelson, 2005; Loppie & Wien, 2022). As a root of disparities, colonization impacts other proximal and distal social determinants of health, such as infrastructure, health behaviours (e.g., diet, physical activity, and smoking), access to resources (e.g., housing and transportation), education, and healthcare systems (Loppie & Wien, 2022).

The United Nations Declaration of the Rights of Indigenous Peoples (United Nations, 2007) affirms that special attention should be paid to Indigenous elders' rights and unique needs. Despite this, dementia risk reduction, assessment, and post-diagnosis care within FNMI communities continue to be incommensurate with stated current and projected healthcare needs. For instance, research suggests that few FNMI people living in rural and remote communities have undergone formal diagnosis compared to urban areas (e.g., Gusul, 2013; Jacklin et al., 2015; Pace et al., 2013). Further, FNMI people are often diagnosed in the later stages of the disease (e.g., Alzheimer's Society of Canada, 2024; Kirkpatrick et al., 2019; Racine et al., 2021), which can delay access to culturally appropriate care, limit opportunities for early intervention

and care planning, and create additional challenges in obtaining necessary supports and making end-of-life decisions. Delayed diagnosis may be due to several barriers to accessing healthcare, related to the social determinants of health, including long waiting lists, distance to services, and a lack of culturally safe care (e.g., Jacklin & Walker, 2020; Loppie & Wien, 2022; Public Health Agency of Canada, 2021, 2019). The social determinants of health and such international policy necessitate dementia care efforts tailored to the unique needs and perspectives of FNMI people.

**Culturally Safe Dementia Risk Reduction, Assessment, and Post-Diagnosis Care**

Cultural safety was initially described by Māori nurse-scholar Irahepti Ramsden (1990; 2000) and used to examine healthcare interactions among Māori in New Zealand and non-Indigenous Peoples. Ramsden (1990) observed that Māori were less likely to use mainstream healthcare services, present at later stages of disease progression, and more likely to not adhere to treatment. Cultural safety was developed to highlight the power imbalances between Māori and the dominant healthcare system, which historically marginalized Māori perspectives on health and illness while prioritizing those of the *Pākehā* (White) culture (Ramsden, 1990; 2000). Unlike cultural sensitivity, which emphasizes awareness of cultural differences, cultural safety explicitly addresses health inequities by recognizing how sociopolitical power structures (e.g., historical, social, political, structural, and systemic imbalances) shape the healthcare experiences of Indigenous Peoples.

While the importance of cultural safety has been emphasized throughout research and healthcare, there is considerable variability in how it is defined and applied (e.g., Tremblay et al., 2020). At an individual level, cultural safety refers to a state whereby a provider engages in critical self-reflection to examine power relationships, identity, and privileges underlying healthcare services and systems. More broadly, however, cultural safety has been defined as all actions that recognize, respect, and nurture the distinct cultural identity of Indigenous Peoples

and other cultural minorities and safely meet their needs, rights, and expectations (e.g., Whakaruruhau, 1991). Such actions can be made at the individual, community, organization, system, or national levels. In Canada, Smye et al. (2010) proposed that culturally safe healthcare for FNMI people requires 1) an understanding of colonization and post-colonial forces and their effect on the lives of FNMI people, 2) a commitment to key principles of FNMI healthcare, including reciprocity, inclusivity, respect, collaboration, community development, and self-redetermination, 3) culturally safe communication and language, and 4) recognition of FNMI knowledges and practices concerning health and wellness and their inclusion as legitimate intervention options. Culturally safe care efforts at varying levels of influence improve patient clinical outcomes, increase patient satisfaction and health professional confidence in providing care to Indigenous Peoples, and increase patient access to healthcare (e.g., Tremblay et al., 2020). Such efforts and principles must be applied within dementia risk reduction, assessment, and post-diagnosis care.

Culturally-safe dementia care refers to any action to create and support the empowerment of cultural identity, sensitivity, and wellness for people with dementia (e.g., Shrestha, 2024). Culturally safe dementia care is necessary, as cultural factors can influence perspectives and needs related to risk reduction, assessment, and post-diagnosis support. For instance, cultural perceptions and explanatory models of health, including dementia, can influence care trajectories, interpretations of symptoms, health-care-seeking behaviours, approaches to caregiving, and treatment preferences (e.g., Kane, 2000; Jacklin & Walker, 2020; Pace, 2020). Help-seeking behaviours (e.g., seeking out assessment and respite care) are also strongly influenced by the self-appraisal of problems and symptoms, which are influenced by sociocultural factors and health beliefs (e.g., Lian et al., 2017). For instance, appraising severe

changes to cognition as a regular part of aging can deter individuals from seeking assessment and care until a major crisis (e.g., Aminzadeh et al., 2012), negatively impacting the health and wellness of the person with dementia and their care partners. In addition, integrating FNMI perspectives of dementia into healthcare communication resources, alongside mainstream health advice, may help to improve dementia health literacy (Webkamigad et al., 2020), which is critical for supporting help-seeking behaviours. Integrating FNMI perspectives into dementia care may also ensure that FNMI spiritual health (e.g., ceremonies and smudging), cultural, and language needs are adequately met through culturally tailored and responsive resources (Chakanyuka et al., 2022).

### *Cultural Perspectives of Dementia Risk Reduction, Assessment, and Post-Diagnosis Care Among Indigenous Peoples*

Diversity exists in how dementia symptoms are interpreted among Indigenous Peoples globally and within Canada. In some First Nations communities in Canada, dementia is interpreted as a natural part of the lifecycle or circle of life (Chakanyuka et al., 2022; Gusul, 2013; Hulko et al., 2010; Jacklin & Walker, 2020; Webkamigad et al., 2022). For instance, healthcare providers who provide services to FNMI elders in Northwestern Ontario reported that many clients perceived dementia as a part of the lifecycle (Gusul, 2013). Accordingly, dementia symptoms may not be interpreted as problematic or part of a disease, influencing assessment and treatment seeking (Finkelstein et al., 2012). However, Jacklin and Walker (2020) note that some FNMI people may report a biomedical understanding of dementia as a disease (Jacklin & Walker, 2020), which may also be the case in Northwestern Ontario among younger generations (Gusul, 2013). Such perspectives may be meaningful to strengthening culturally safe dementia care efforts, such as healthcare communication resources.

Indigenous Peoples also hold diverse perspectives on the risk factors of dementia. For instance, dementia symptoms have been described as caused by physiological (e.g., genetics), psychosocial (e.g., trauma), and cultural factors (e.g., disruptions to land-based activities) among FNMI people (e.g., Jacklin & Walker, 2020). Similarly, physical inactivity, changes in land-based diets due to colonization, medical conditions, and environmental toxins were identified as factors that increase dementia risk among Māori (Menzies et al., 2022). These perspectives may help to further our understanding of risk factors for dementia and identify culturally relevant approaches to addressing risk reduction in FNMI communities and beyond.

Cultural perspectives on risk reduction also highlight the importance of relationships, or kinship networks (i.e., relationships with family, community, non-human kin, land, and water). For instance, maintaining social connections helps define aging well among Indigenous Peoples globally (Quigley et al., 2022). Further, supportive family and social networks (e.g., visiting social gatherings and telling stories), attending community meetings, and engaging in group activities (e.g., singing) have been identified as essential to aging well by supporting cognitive health, memory, and cultural identity among Southern Inuit (Pace, 2020) and Māori (Menzies et al., 2022). To be culturally safe and effective, these perspectives must be integrated into risk reduction strategies.

Indigenous Peoples also hold diverse perspectives on the relevant symptoms that should be assessed among people at risk for or living with dementia. Recent research with Māori communities suggests that, in addition to a formal cognitive assessment, other culturally relevant symptoms, such as changes to involvement in community roles or with grandchildren, abilities to help others, and sense of connection to land, should be examined when assessing for dementia (Menzies et al., 2022). Similarly, a quality of life assessment tool developed with Aboriginal

elders in Australia highlights unique domains of well-being, including spending time on the land, feeling connected to community and cultural practices, spiritual safety and support, and opportunities to share knowledge and stories with younger generations (Gilchrist et al., 2023). These findings indicate the importance of assessment tools that reflect Indigenous worldviews and living experiences, which can more effectively guide risk reduction strategies and post-diagnosis treatment planning and care.

Many Indigenous Peoples prefer to age with dementia at home in their community (i.e., aging in place), which supports wellness and retains connection to and engagement with kinship networks (e.g., Cox et al., 2019; Jacklin & Walker, 2020; Pace, 2020). To support aging in place, many Indigenous families and communities provide care (i.e., informal care partners) for family members living with dementia, guided by cultural values such as the centrality of the family and high respect for elders (e.g., Browne et al., 2019; Gusul, 2013; Menzies et al., 2022; Webkamigad et al., 2020). These care preferences are rooted in a wholistic and collective view of care, where well-being is shared across individuals, families, and communities (e.g., Haydon et al., 2022; Henderson et al., 2024). Moreover, some FNMI people living with dementia may choose not to engage with services grounded in Western healthcare systems, even as their condition progresses (Henderson et al., 2024). However, informal caregiving may occur due to necessity, particularly in rural and remote areas where limited formal care alternatives exist (Gusul, 2013; Jacklin & Walker, 2020). Moreover, not all Indigenous Peoples living with dementia have access to supportive family members, which can limit their ability to remain in the community as they age with dementia (Menzies et al., 2022; Racine et al., 2021).

Caregiver burden, a subjective adverse effect on functioning due to caregiving and a conflict between caregiver needs and care-recipient demands, is often reported among informal

care partners (e.g., Chiao et al., 2015). While some Indigenous care partners report a sense of reward and purpose in providing care (e.g., Browne et al., 2021), they also report elevated distress, including emotional stress, anxiety, and financial strain (e.g., Gusul, 2013; Jacklin & Walker, 2020; Menzies et al., 2022; Webkamigad et al., 2020). These challenges are further complicated by geographic isolation and systemic inequities in access to health and social services, such as culturally safe respite and psychoeducation programs (e.g., Racine et al., 2021). In some cases, when the care needs of the person living with dementia exceed the capacity of family members, relocation outside of the community may become necessary (e.g., McAtackney et al., 2021), disrupting important connections to community, culture, and land that are integral to aging well in Indigenous worldviews (e.g., Pace, 2020).

Given these realities, integrating FNMI perspectives of dementia risk reduction, assessment, and post-diagnosis care remains critical to supporting culturally safe dementia care for FNMI people. To ensure culturally safe dementia initiatives, it is equally important to identify and strengthen existing community supports that align with these perspectives, values, and priorities. This includes recognizing the strengths, resources, and relationships that already exist within communities and supporting approaches that are community-driven and grounded in self-determination.

### *Relational Supports for Culturally Safe Dementia Risk Reduction, Assessment, and Post-Diagnosis Care in Indigenous Communities*

The principles of collaboration, community development, and self-determination within culturally safe care (Smye et al., 2010) underscore the importance of working with communities to identify and strengthen locally available resources to improve culturally safe care, rather than imposing external solutions. Health asset mapping is a strengths-based approach to identifying, mobilizing, and building on existing community assets to address community-level concerns,

such as health disparities and inequities (e.g., Cassetti et al., 2019; Lightfoot et al., 2014; 2016; Luo et al., 2023; Shahid et al., 2019). Health assets may include individuals, associations, institutions, land and the physical environment, exchange networks (e.g., social support groups), and culture (e.g., cultural practices and social gatherings). Assets can be mobilized by connecting existing assets (e.g., connection associations with common goals), raising awareness of assets (e.g., developing resources to communicate existing assets), and enabling assets to thrive (i.e., further developing assets) (e.g., Cassetti et al., 2019). Given these principles, health asset mapping may be an effective approach in better supporting self-determined approaches to culturally safe dementia care.

Ecological models of health have been used as a framework with health asset mapping to identify the assets at individual, interpersonal, and community levels that promote health and wellness (e.g., Cassetti et al., 2019). According to such models, health behaviours, including those that support disease risk reduction, assessment, and post-diagnosis care, are maximized when the environmental context supports healthy choices (e.g., affordable fitness facilities) and when individuals are motivated and informed (e.g., to engage in exercise) (Sallis et al., 2008). Aligned with the social determinants of health, ecological models are often used to examine mutually influencing factors on health behaviours. These include individual factors (e.g., health behaviours and psychological factors, such as motivation and self-efficacy) and interpersonal factors (e.g., social relationships and support) (Sallis et al., 2008). While there are multiple types of ecological models, core principles of ecological models include 1) there are multiple factors that influence health behaviour (e.g., individual and interpersonal), 2) influences interact across levels (e.g., individual qualities, such as motivation to exercise, interact with access to affordable fitness classes), 3) health is a result of the person and environment fit, and 4) interventions that

address multiple factors will be most effective at improving health behaviour (Grzywacz & Fuqua, 2000; Sallis et al., 2008; Stokols, 1992). Given the use of ecological models in identifying health assets to support health and wellness (e.g., Cassetti et al., 2019), these models provide a useful framework for identifying health assets to better support culturally safe dementia risk reduction, assessment, and post-diagnosis care in FNMI communities.

Aligned with ecological models, dementia within Indigenous communities is influenced by the interconnectedness between individuals, families, kinship networks, communities, and land (e.g., Haydon et al., 2022). However, Indigenous researchers and allies have advocated using Indigenous theories and perspectives in dementia research and clinical work (Haydon et al., 2022; Webkamigad et al., 2022; Wettasinghe et al., 2020). Nishnaabe wholistic theory and similar Indigenous social determinants models of health (e.g., Loppie & Wien, 2022) have been used extensively for health promotion research (e.g., Mashford-Pringle & Shawanda, 2023). Nishnaabe wholistic theory underlines the interconnectedness of individuals with family, community, nation, society, and creation, with each level influenced by historical, social, political, and economic contexts and factors (Absolon, 2019). Moreover, health is more readily achieved when each level is balanced and harmonious (Absolon, 2019). This theory is well-aligned with modern ecological model theorists who also emphasize the importance of individual and environmental fit for health. Accordingly, Nishnaabe wholistic theory can guide the identification of individual, interpersonal, and community-level health assets that support culturally safe dementia risk reduction, assessment, and post-diagnosis care among FNMI people.

While the term health asset is commonly used in the literature, this framing can implicitly objectify, reify, commercialize, and commodify FNMI supports and reduce them to mere static

resources, such as cultural identity and connection to land, which are instead deeply relational, spiritual, and sacred. While drawing on strengths-based and asset mapping frameworks, I aim to honour these elements as living relationships rather than static resources. Accordingly, I use the term relational supports in place of assets.

**Wholistic Relational Supports Among Indigenous Communities**. Connection to culture and cultural identity, an individual-level relational support, influences dementia risk reduction behaviours. For instance, connection to culture (e.g., cultural identity, spirituality, and traditions) was predictive of increased physical activity (e.g., strength training and other traditional activities that include physical activity, such as trapping) among First Nations adults in Saskatchewan (Ironside et al., 2020). Enculturation, or the degree to which an individual identifies with their Indigenous culture, was also associated with increased physical activity and decreased hypertension, alcohol abuse, and stress among Indigenous Peoples in the United States (Burnette et al., 2020). Further, acculturation (e.g., identification with the dominant Western culture) predicted utilizing substances (e.g., alcohol) to cope, whereas enculturation predicted utilizing religion and spirituality for coping (Burnette et al., 2020). Cultural identity further predicted smoking status among Indigenous adolescents in Australia, New Zealand, Canada, and the United States (Heris et al., 2020), healthy eating habits among Aboriginal and Torres Strait Peoples in Australia (Christidis et al., 2021), and type 2 diabetes among First Nations Peoples in Canada (Oster et al., 2014). These findings suggest that cultural identity and connection to culture may be protective factors against risk factors for dementia.

One component of cultural identity is a sense of and engagement with a connection to the land. Connection to land can facilitate dementia primary and secondary risk reduction practices among Indigenous Peoples, such as increased physical activity, cognitive stimulation, and

healthy diet consumption (e.g., Menzies et al., 2022; Freeman et al., 2022; Pace, 2020). Further, proximity and a connection to land helps to support cultural identity after a dementia diagnosis (Henderson et al., 2024; Pace, 2020), memory recollection and orientation (Pace, 2020), and cognitive health (Cavuoto et al., 2024). These findings suggest that connection to land is a relational support that can facilitate risk reduction and post-diagnosis care among Indigenous Peoples.

Interpersonal relational supports also support dementia risk reduction, assessment, and post-diagnosis care. Informal care partners support risk reduction activities (e.g., physical activity), assessment (e.g., communicating information about symptoms), and post-diagnosis care (e.g., communicating care preferences and changes in symptoms to healthcare providers and coordinating formal caregiving) (Bryant et al., 2021; Ismail et al., 2020; Lian et al., 2017). Moreover, informal care partners facilitate post-diagnosis at-home care by completing formal caregiving services (e.g., preparing meals) (Finkelstein et al., 2012; Gusul, 2013). Communities further assist elders living with dementia in the community, such as monitoring for wandering behaviours, and supporting those without immediate family (Jacklin & Walker, 2020).

Within many Indigenous communities, elders often have traditional roles that may help to foster risk reduction and post-diagnosis care (Menzies et al., 2022; Pace, 2020). While significant diversity in traditional roles exists between Indigenous communities, some recognized roles include teaching younger generations and supporting community members (e.g., Cornet Benoit et al., 2020; Pace, 2020). Traditional roles fostering intergenerational relationships with youth may help to promote cognitive health among youth and elders, including those living with dementia (e.g., Cornet Benoit et al., 2020), facilitating dementia risk reduction. Further, family roles may help motivate elders to care for their health and fulfill grandparent roles (Webkamigad

et al., 2020). Notably, disrupting traditional roles may be related to memory loss and cognitive decline among FNMI people (Jacklin & Walker, 2020), further supporting their role as relational supports in risk reduction and post-diagnosis care.

Healthcare providers' knowledge of dementia is also a relational support for dementia risk reduction, assessment, and post-diagnosis care. Healthcare professionals (e.g., primary care physicians) use their training and experience to assess and advise at-risk individuals, recognize early and progressing symptoms, determine treatment needs, conduct health assessments, manage symptoms, and understand client needs (e.g., Bryant et al., 2021; Ismail et al., 2022). Properly trained primary care physicians can clearly explain the condition, diagnostic process, and post-diagnosis care options, which helps to reduce anxiety for people living with dementia and informal care partners (e.g., Aminzadeh et al., 2012; Finkelstein et al., 2012; Freeman et al., 2022). However, in some Indigenous communities, the ability of healthcare providers to identify, screen, and support post-diagnosis dementia care is often limited, which can restrict their ability to provide care competently (Haydon et al., 2022). Primary care physicians in rural and remote Indigenous communities may be especially disadvantaged in their dementia knowledge and clinical skills (Haydon et al., 2022), further negatively impacting effective risk reduction, assessment, and post-diagnosis care.

Healthcare providers' culturally safe practices are also a relational support for dementia risk reduction, assessment, and post-diagnosis care. Indigenous Peoples’ experiences of racism, discrimination, and prejudice within healthcare systems are well-documented (e.g., Turpel-Lafond, 2020). These experiences negatively impair access to dementia care, such as challenging respectful working relationships between healthcare providers and Indigenous Peoples in Canada (e.g., McAtackney et al., 2021), Australia (e.g., Bryant et al., 2021), and globally (e.g.,

Henderson et al., 2024). Healthcare providers providing culturally safe and competent services can help reduce the prevalence of racist, discriminatory, and prejudiced experiences in healthcare systems (Chakanyuka et al., 2020), which may help to reduce barriers to healthcare access. Culturally safe dementia care practices include cultivating and expressing a commitment to build relationships with local Indigenous communities, understanding and respecting Indigenous values, beliefs, culture, and history, integrating Indigenous cultures into healthcare practice (e.g., healing practices), engaging in culturally respectful communication, and using Indigenous languages in client exchanges (Bryant et al., 2021; Chakanyuka et al., 2022; Finkelstein et al., 2012; Gusul, 2013; Hulko et al., 2021; Patel et al., 2022; McAtackney et al., 2021; Webkamigad et al., 2022).

Community-level relational supports also aid dementia risk reduction, assessment, and post-diagnosis care. Access to culturally appropriate dementia psychoeducation resources reduces stigma, denial, and symptom concealment, facilitating risk reduction, earlier diagnosis, and access to treatment and support. Psychoeducation may include risk factors and reduction strategies, symptoms, advantages of timely diagnosis, available local services (e.g., support groups), and skills and strategies for caring for people living with dementia (e.g., Bryant et al., 2021; Browne et al., 2019; Cox et al., 2019; Racine et al., 2021; Finkelstein et al., 2012; Gusul, 2013; Lian et al., 2017; Patel et al., 2022; Webkamigad et al., 2020; Webkamigad et al., 2022). Access to these resources improves the quality of life for Indigenous Peoples living with dementia, reduces informal caregiver distress, alleviates strain on healthcare systems, supports aging in place, and promotes community-wide caregiving (e.g., Cox et al., 2019; Gusul, 2013; Kenning et al., 2017; Lian et al., 2017; McAtackney et al., 2021; Racine et al., 2021; Sideman et al., 2022). Importantly, psychoeducation resources should reflect local Indigenous knowledge,

language, values, and approaches to health information communication (e.g., storytelling, visual images, discussion in small groups) and education attainment (e.g., Bryant et al., 2021; Finkelstein et al., 2012; Gusul et al., 2013; Racine et al., 2021; Webkamigad et al., 2022).

Local and culturally safe healthcare services are also a relational support**.** Regular access to healthcare services is negatively associated with the incidence of dementia (Li et al., 2023). Local and telehealth healthcare services (e.g., within or in proximity to Indigenous communities) may also facilitate dementia risk reduction (e.g., reduced prevalence of modifiable risk factors; Anand et al., 2019), assessment, and aging in place (e.g., Anand et al., 2019; Gusul et al., 2013; Haydon et al., 2022; Jacklin & Walker, 2020; Starblanket et al., 2019; Wadsworth et al., 2016). For instance, local healthcare services can support elders to age in their communities, thereby fostering cultural connectedness and social connections and reducing isolation and distress (e.g., Gusul, 2013). Local meaningful services include memory clinics, rehabilitation, respite facilities, affordable home maintenance services, counselling, health promotion services (e.g., walking groups), crisis support, medical transportation services, palliative care and advance care planning programs, and long term care, including facilities managed by Indigenous communities or organizations (e.g., Aminzadeh et al., 2012; Browne et al., 2019; Bryant et al., 2021; Cox et al., 2019; Bello-Hassan et al., 2014; Finkelstein et al., 2012; Gusul, 2013; Ismail et al., 2020; Jacklin & Walker, 2020; Lian et al., 2017; Livingston et al., 2020; McAtackney et al., 2021; Pace, 2020; Patel et al., 2022; Walker et al., 2018). Local healthcare services can ensure culturally relevant and safe care by integrating Indigenous culture into healthcare, developing initiatives to reduce language barriers and promote respectful communication, facilitating access to spiritual care (e.g., ceremonies and smudging) and spaces for traditional ceremonies, developing and enforcing organizational mandates, monitoring, and evaluation to support cultural safety in healthcare,

programs and initiatives to assist ethnic minorities in navigating healthcare systems, and family-directed respite programs to foster family-led respite care (Chakanyuka et al., 2022; Finkelstein et al., 2012; Gusul, 2013; Kenning et al., 2017; Patel et al., 2022).

Local healthcare and community-based culturally relevant programming are also a relational support. Programs for FNMI people at-risk or living with dementia and informal care partners attended independently and jointly can facilitate risk reduction and post-diagnosis care. Programs for FNMI people at-risk or living with dementia have included psycho-social support programs, such as dementia-inclusive and culturally relevant physical activity programs (e.g., walking groups), diabetes management programs, and smoking cessation programs, regular elder gatherings with traditional foods and music (e.g., singing groups), including gatherings with traditional foods and music, inclusion in community gatherings (e.g., festivals and potlatches), dance and art programs, land-based activities, intergenerational programming for elders and youth, mindfulness programs, and day programs (e.g., nutrition bingo and crafts) (e.g., Bantum et al., 2024; Bechard et al., 2020; Browne et al., 2019; Cornect Benoit, 2020; Dodds & Siette, 2022; Gusul, 2013; Lavrencic et al., 2022; Menzies et al., 2020; Pace, 2020; Racine et al., 2021; Webkamigad et al., 2022).

Community-based support programs for informal care partners are also a relational support for dementia care. Such programs can reduce caregiver burnout, improve mental health and wellness, and help people living with dementia age in place (e.g., Livingston et al., 2020). When culturally relevant and accessible, programs strengthen care networks and improve quality of life for the care partner and the person living with dementia. Effective support programs for risk reduction and post-diagnosis care include behavioural therapy, stress management, grief support, family-based social and group support networks with other Indigenous informal care partners,

land-based activities, attending cultural events, emotional support during end-of-life and social service programs and supports, developed with consideration to cultural relevance and safety (e.g., Bello Hassam et al., 2014; Browne et al., 2019; Cox et al., 2019; Finkelstein et al., 2021; Gusul, 2013; Haydon et al., 2022; Kenning et al., 2017; Pace, 2020; Racine et al., 2021; Webkamigad et al., 2022).

The physical environment of communities can also facilitate dementia risk reduction and post-diagnosis care. For instance, community resources such as exercise equipment, indoor and outdoor recreation centres, greenspace, accessible transportation, and housing (e.g., seniors apartments and supportive housing), especially within Indigenous communities, are critical to effectively addressing risk factors and caring for people living with dementia (Bechard et al., 2020; Bryant et al., 2021; Cavuoto et al., 2024; Bello Hassam et al., 2014; Freeman et al., 2022; Gusul, 2013; Kirychuk et al., 2022; Lawton, 1972).

### Cultural Perspectives and Wholistic Relational Supports for Dementia Risk Reduction, Assessment, and Post-Diagnosis Care among FNMI in Northwestern Ontario

While some previous studies have examined the unique perspectives of dementia and relational supports for risk reduction, assessment, and post-diagnosis care in FNMI communities in Canada and Indigenous communities globally, the relationality of Indigenous knowledge to a particular community or nation makes it impossible to generalize to other contexts (McGregor et al., 2018). In other words, pan-Indigenous approaches to dementia care are unlikely to yield optimal results across all Nations and communities (Hulko et al., 2010). Instead, there is a need for community-based dementia care for FNMI communities that is culturally relevant, strengths-based, and context-dependent (Smye et al., 2010). Accordingly, community and regional-based approaches are most effective.

Northwestern Ontario is a diverse geographic area composed of urban cities (e.g., Thunder Bay, Kenora, Dryden), small rural and remote communities (including those solely accessible by air and marine transportation), and many First Nations communities (Government of Ontario, 2011; Statistics Canada, 2023). This region also has a higher population density of FNMI people. For instance, 12.7% of people living in Thunder Bay, Ontario, self-identify as First Nations, Métis, and/or Inuit, compared to 2.8% within Ontario (Statistics Canada, 2025). While academic researchers have begun to examine FNMI perspectives of dementia, risk reduction, assessment, and post-diagnosis care (e.g., Jacklin & Walker, 2020), these perspectives have not yet been examined by academic researchers in Northwestern Ontario, despite research suggesting dementia is a growing concern in this region (Alzheimer's Society of Thunder Bay, 2023; Gusul, 2013). Without fully understanding these perspectives, healthcare systems and providers are limited in understanding needs, strengths, and pathways to care. Moreover, while research points to several critical relational supports that facilitate dementia care within Indigenous communities globally, and FNMI communities more specifically, it is unclear whether these relational supports are relevant or present within FNMI communities in Northwestern Ontario. No published research examines relational supports that may support improved culturally safe dementia risk reduction, assessment and post-diagnosis care in this region.

A distinctions-based approach strengthens the relevance of health research. A distinctions-based approach requires that those who inform and support healthcare services engage in their work in a way acknowledges the specific rights, interests, priorities, and concerns of FNMI people and communities, while respecting and acknowledging their unique cultures, histories, rights, laws, and governments (Government of British Columbia, 2024). Such an approach necessitates considering the perspectives of individuals from diverse FNMI identities, gender

identities, and geographical locations of residence (i.e., rural or urban). This is imperative, given the cultural diversity among FNMI people and communities. Moreover, LGBTQ2S+ elders, compared to their peers, may experience unique care preferences and experiences (e.g., higher social isolation) (Wilson et al., 2019). Geographic factors, such as whether an individual resides in an urban or rural community, can also greatly influence access to healthcare services and other health-promoting relational supports. Accordingly, a distinctions-based approach is necessary to appropriately improve culturally safe dementia care.

To address these gaps in the literature and community-identified needs, I examined the cultural perspectives of dementia symptoms, risk reduction, assessment, and post-diagnosis care among FNMI people in Northwestern Ontario and the individual, interpersonal, and community-level relational supports that may support culturally safe dementia efforts. This research is necessary for several reasons. First, culturally safe dementia care has been identified as a priority by a regional First Nations-led health organization in Northwestern Ontario that provides services to FNMI elders. I have responded directly to this community-identified need by examining cultural perspectives and relational supports that can be applied to program development, training, and culturally grounded dementia guidance. These contributions may support improved case-finding, assessment, risk reduction, and post-diagnosis care for FNMI individuals living with or at risk for dementia in Northwestern Ontario. Second, this research may contribute to local, provincial, and national policy and funding decisions by contributing to the literature the unique perspectives and needs of FNMI people concerning dementia risk reduction, assessment, and post-diagnosis care. Lastly, this research contributes to national priorities outlined in Canada's national dementia strategy (Public Health Agency of Canada, 2023), including dementia risk reduction, improved assessment, and post-diagnosis care. Aligned

with the strategy's guiding principle of Respect and Value Diversity, this research affirms the distinct needs of FNMI people and emphasizes the importance of community involvement in ensuring culturally appropriate and safe care. It supports risk reduction among FNMI people by identifying cultural understandings of brain health and relational supports that can inform future interventions, psychoeducation efforts, and public health policies. It also improves the quality of life for individuals with dementia and their care partners by highlighting culturally grounded perspectives of care and approaches to assessment and caregiver support. Additionally, it responds to the strategy's call for culturally safe assessment tools by identifying culturally relevant understandings of dementia symptoms.

**The Present Study**

In this thesis, I examined cultural perspectives of dementia symptoms, risk reduction, assessment, and post-diagnosis care among FNMI people in Northwestern Ontario and the individual, interpersonal, and community-level relational supports that support these pillars of care. I examined:

1. What are the meaning and culturally relevant symptoms of dementia among FNMI people in Northwestern Ontario?
2. What does it mean to reduce risk, assess, and support others with dementia among FNMI people in Northwestern Ontario?
3. What individual, interpersonal, and community relational supports in FNMI communities in Northwestern Ontario facilitate risk reduction, assessment, and post-diagnosis care?
4. How do FNMI identity, gender identity, and geographical location (rural and urban) impact these perspectives?

# Method

## Research Design Overview

In this thesis, I utilized a community-engaged approach, guided by a Nishnaabe research paradigm (e.g., Wilson, 2008). I partnered with Dilico Anishinabek Family Care (Dilico), a regional First Nations-led organization in Northwestern Ontario with health, mental health, addiction, and child welfare mandates. I collected stories[5] using in-person knowledge-gathering circles (e.g., Baskin, 2005) and one-on-one and two-on-one in-person and virtual interviews, and analyzed them using reflexive thematic analysis (Braun & Clarke, 2006; 2021). All aspects of my research were guided by the community partner's research advisory committee and a community advisory committee of healthcare workers and managers.

## The Gift is in the Making: A Michi Saagiig Nishnaabeg Research Paradigm

Research paradigms, including ontology (e.g., beliefs about reality), epistemology (e.g., beliefs about knowledge), axiology (e.g., ethics), and methodology (e.g., research approach and methods), inherently inform all researchers' work. Kovach (2009) shared that naming and describing a research paradigm allows Indigenous researchers to acknowledge the cultural knowledge that guides research decisions, such as methods and approaches to interpretation. An increasing number of Indigenous researchers utilize and name the cultural worldviews and values that guide their work (Wilson, 2008). This can be a potent act of decolonization, whereby Indigenous researchers choose and are given the space to utilize different ways of thinking and doing research that resist the ongoing colonialism in research (McGuire Adams, 2020). Nishnaabe knowledge, which encompasses values, ethics, and ways of being, primarily guided me in the present research.

[5] I use the word stories instead of data to honour the personal, contextual, and living knowledge offered by knowledge collaborators.

In this thesis, I used a research paradigm inspired by Michi Saagiig Nishnaabeg knowledge, articulated through a story, *The Gift is in the Making* (Simpson, 2013). At the surface, The Gift is in the Making is a classic story of Nanabush (a Nishnaabeg supernatural being), who comes across Michi Saagiig Nishnaabeg neglecting their responsibilities and drinking ziiyaagmide (maple syrup) all day, consults Nokomis (grandmother), who teaches Nanabush how to turn the ziiyaagmide back into sap so that the Michi Saagiig Nishnaabeg must work together to make it. Nanabush teaches the Michi Saagiig how to make ziiyaagmide, and this practice is now engaged with every year. While this interpretation captures the surface-level meaning of this story, the story has multiple deeper meanings and points of significance that are impossible to articulate fully. Respecting the autonomy of knowledge, stories can have diverse meanings depending on a listener's or reader's point in life. Therefore, listeners can take different meanings from stories, depending on their developmental point and needs.

This relational understanding of knowledge and knowing reflects Nishnaabeg's relational ontology. Positivist ontological positions, which often implicitly characterize research conducted in academic institutions, posit a singular and objective reality independent of human interpretation (Wilson, 2008). In contrast, Nishnaabeg ontology recognizes multiple realities accessed through relationships and spiritual and physical means (McGuire, 2013). Knowledge is understood as personal and relational; objectivity and a singular truth are impossible (McGuire, 2013). Moreover, “relational understandings, you, your family, community, and other relationships, including the spiritual world, are fundamental to Nishnaabeg knowledge (…) the basis for truth within Nishnaabeg communities is personal” (McGuire, 2013, p. 10). Accordingly, how I interpreted The Gift is in the Making and allowed it to ground this research was deeply

relational. Likewise, how I interpreted the stories shared with me in this research was similarly subjective and relational.

### *Epistemology and Axiology*

Epistemology describes knowledge's nature, origins, and limits, including beliefs about acquiring knowledge (Wilson, 2008). Ontology is related to epistemology, as beliefs about reality help determine how we learn more about reality (Wilson, 2008). From a relational ontological perspective, acquiring knowledge requires loving and respectful relationships, including with self, others, land, and the stories gathered (Wilson, 2008). Absolon (2011) further stated that the embodied nature of the pursuit of knowledge "requires us to walk and to dwell" and "an attunement to the embodied landscape as a primary way of coming to know ourselves about others" (p. 8). This embodied landscape includes our thoughts, dreams, and emotions (Absolon, 2011; Simpson, 2014). Relationality also underscores the importance of connection to land when conducting research. The concept of gikendaasowin (knowledge) is derived from the concept of gikendaaso (to know, to be intelligent). Similarly, gikinawaabiwin means to learn by observation (Stark, 2021). This term is related to gikinoo'amaage, which means to teach (Stark, 2021). Lastly, this term is related to the aki, which means land. The relationships between these words suggest that Nishnaabeg research is an embodied process of coming to know connected to the land and recognizing the agency of knowledge, whereby Nishnaabeg can co-construct knowledge through the land (e.g., Wilson, 2008).

Relationality also emphasizes the importance of collaborative community-based relationships. Within Nishnaabeg thought, truth is understood as a collective understanding of all community members (Stark, 2021). In traditional governance, decisions that impact the community are made collaboratively, where each community member can state their truth; the collaboration of truth is then considered the collective understanding (Stark, 2021). These

epistemological perspectives are clearly articulated to me in The Gift is in the Making, whereby Nanabush learns through engaging in collaborative relationships with Nokomis, aki, and visiting and sharing knowledge with the Michi Saagiig Nishnaabeg community, grounded in a foundation of love and respect.

The Gift is in the Making also teaches me that the value of our actions lies not only in the outcome of whatever we do but also in the process itself. For instance, in the story, Simpson (2013) states:

> They [the Michi Saagiig Nishnaabeg] cherish the gift given to their ancestors so long ago, and in their heart knowledge, hidden away in the most precious parts of their beings, they know that ziinzibaakwad [maple sugar] wasn't the real gift. They know that the gift is in the making, and that, without love, making just wasn't possible (p. 92).

While the outcome of making ziinzibaakwad provides nourishing food, the process of making, which includes building good relationships with our kinship networks, including our families and the land, and regenerating cultural traditions and values to other generations, is the real gift. Likewise, the process and outcome of research can also be gifts. McGregor et al. (2018) state that "Indigenous research holds the potential to regenerate and revitalize the life of Indigenous Peoples and communities along with the 'knowing' that sustains their ongoing vitality" (p. 2). While the research findings of this research are valuable to promoting brain health among FNMI people in Northwestern Ontario, I sought for the research process itself to be a gift by promoting and sustaining brain health, biskaabiiyang (returning to ourselves, i.e., cultural resurgence), mnaadendimowin (respect), good relationships, and transformative learning in the way it is conducted.

***Methodology***

Grounded in the teachings that I have gathered from The Gift is in the Making, my research methodology was guided by an axiology rooted in biskaabiiyang, good relationships, mnaadendimowin, and transformative learning. This approach is like community-based research methodologies but is distinctively led by Nishnaabeg worldviews, ways of knowing, and values.

Cultural resurgence, or biskaabiiyang, is a value that firmly guided me in this work. Michi Saagiig Leanne Betasamosake Simpson (2017) shared that "biskaabiiyang is a verb that means to look back" (p. 49). Within scholarly work, Nishnaabe researchers have used biskaabiiyang to describe a process of "returning to ourselves"; of evaluating the role of colonialism in our lives and picking up "the things that we were forced to leave behind, whether they are songs, dances, values, or philosophies, and bring them into existence in the future" (Simpson, 2017, p. 50). Moreover, biskaabiiyang is a research process whereby Nishnaabeg evaluate how they have been personally impacted by colonization and work towards returning to their ancestral ways of being (Simpson, 2017). Importantly, biskaabiiyang does not necessitate returning to a past state of being or promote an essentialist understanding of Nishnaabeg identity (Simpson, 2017). Instead, it is an ongoing process by which each Nishnaabe figures out how to live as Nishnaabeg in the contemporary world, embraced and guided by our processes, values, and philosophies embedded in our language and culture. Moreover, given that our political and social systems are non-hierarchical, non-authoritarian, and non-coercive, and promotes aanjigone (an ethic of non-interference or autonomy), central to biskaabiiyang is an acknowledgment of the diversity in how each person engages in this personal and collective work (Simpson, 2017).

As Nishnaabeg, we are encouraged to find and develop our gifts and use them to contribute to our communities and Nation. Naturally, this thesis became a medium through which I developed and applied some of my gifts, or skills and capacities, to promote brain health and

healthy aging within the Nishnaabe Nation, which was realized throughout the research methodology. Aligned with a relational epistemology, I was also mindful of and listened to dreams and recurring symbols that appeared during this work. I also spent time on the land before and after each knowledge-gathering circle in the respective communities, where I reflected on the research and on the stories that were shared. I offered semaa (tobacco) to the land in each community I visited to honour the learning that took place. I continuously reflected on how colonial thinking surfaced in my thoughts and behaviours and, in collaboration with my supervisor, sought to address these where possible.

One example of this was my reflections after I conducted my first interview for this research. Although I intended to use a relational approach, I fell into a more Westernized interviewing model, including avoiding self-disclosure and using a more structured format. After the interview, I felt uneasy and inauthentic. Later, I journaled about how I felt, why I might feel that way, and how to respond. I revisited a reading I had encountered during my undergraduate studies on the conversation method (Kovach, 2010), and I realized this approach better aligned with the relationship-based engagement I sought. I consulted with my supervisor and adopted the conversation method moving forward. This approach enabled me to be more aligned with my intention of bringing my whole, authentic self into a relationship with knowledge collaborators.[6] A few knowledge collaborators commented that they appreciated the relational and conversational style and that our time together did not feel like an interview.

**Community Partner Engagement and Data Management.** Biskaabiiyang, mnaadendimowin, good relationships, and transformative learning informed my work with the

[6] I use the term knowledge collaborator in lieu of participant to honour a cultural and relational approach and reflect the collaborative nature of meaning making.

community partner. The present community-based study partnered with Dilico, a regional First Nations-led organization in Northwestern Ontario offering culturally-based child welfare, health services, and mental health and addiction services to FNMI people (infants to elders), families and communities in the Robinson Superior Treaty Area, including 13 local First Nation reserves and the city of Thunder Bay, Ontario (Dilico, n.d.). Resource extraction has a long and ongoing history in Northwestern Ontario, carried through traditional knowledge (e.g., Nanabijou; Carbon, 2019). Care and attention were paid to ensure that knowledge, as a resource, was not similarly extracted from these territories and community members. Accordingly, to respect the territory and knowledge of the region, knowledge sources and ownership were acknowledged and upheld, and I worked to ensure that the co-produced knowledge continued to be relevant and impactful to the community.

Aligned with this intention, I adhered to all aspects of Ownership, Control, Access, and Possession (OCAP®), a set of principles that detail how First Nations' data should be collected, managed, and shared within research (Schnarch, 2004). The Ownership principle stipulates that a community or organization owns all cultural knowledge, data, or information (Schnarch, 2004). The Control principle states that communities and organizations must retain control over all aspects of research and information management (Schnarch, 2004). The Access principle affirms that First Nation communities and organizations have a right to manage and make decisions regarding access to their personal information (Schnarch, 2004). Finally, the Possession principle affirms that First Nation communities and organizations have a right to physically possess or steward their data (Schnarch, 2004).

In line with OCAP®, this research was approved by and received ongoing guidance from Dilico's Research Advisory Board. Dilico's Research Advisory Board reports to and receives

approval for new research projects from a Board of Directors, which includes Chiefs, Band Councillors, and healthcare professionals. Together, they help to determine relevant research initiatives and activities for the 13 First Nations that Dilico serves (Toombs, 2021). The Research Advisory Board reports to and receives approval from the Board of Directors for research activities and maintains control and oversight over all research activities (Toombs, 2021). My supervisor, Dr. Christopher Mushquash, has a longstanding partnership with Dilico and has partnered with them on multiple health and wellness research projects. My supervisor and I approached the Research Advisory Board in the winter of 2024 to discuss the interest and relevance of dementia and brain aging research. The Research Advisory Board affirmed that this was a needed area of research and asked that we consult with the organizations' health leadership for additional feedback and guidance. Likewise, the health leadership team affirmed the need for brain aging and dementia research to serve community members better.

Aligned with the principle of Control, Dilico owns and manages all data produced from this research. Data were temporarily stored within a research laboratory at Lakehead University and will be held indefinitely at Dilico's primary office. Dilico maintains the right to guide and approve all future dissemination initiatives (e.g., journal publications, community presentations, conference presentations). Knowledge collaborators also asserted control over their data, through having the opportunity to review and revise their transcripts and withdraw their data up to 2 weeks after data collection. All knowledge collaborators were also offered the ability to review and provide feedback on the initial results.

**Community Advisory Committee.** To ensure that Dilico's perspectives, needs, and priorities were continuously integrated into this project and that Dilico maintained control over the project, I developed a community advisory committee with Dilico healthcare leaders and

workers. I formally met with the community advisory committee seven times from September 2024 to June 2025. At the start of our time together, we gathered to develop a set of responsibilities and values (e.g., reciprocity), and I offered gifts to each committee member. Our meetings typically began with a territory acknowledgement, prayer, and, to support transformative learning, information on dementia (e.g., risk factors). I also attended quarterly meetings with the Research Advisory Board to provide updates on the project and elicit feedback as needed.

The community advisory committee helped to guide the development of the project objectives, recruitment approaches, data collection methods and locations, and interpretation of findings. The community advisory committee was also engaged to determine the best approaches to local and regional community engagement and dissemination strategies. For instance, at the community advisory committee's request, I presented the research proposal to the Dilico Elders and Youth Advisory in Fall 2024 to elicit feedback, guidance, and insights into the project and invite Elders to the community advisory committee. Despite this, I could not confirm an Elder on the community advisory committee.

**Knowledge Collaborator Recruitment Process and Selection.** A community sample of FNMI adults with an interest in, living experience of, or experience supporting others with dementia was recruited for this study. I used purposive sampling, recruiting knowledge collaborators interested in the research topic and willing to participate. Recruitment was primarily conducted through Dilico. Knowledge collaborators were recruited through word-of-mouth, Dilico's quarterly newsletter, posters and flyers at Dilico's healthcare offices in Thunder Bay, Ontario and several regional offices, referral through Dilico's primary healthcare, cultural health, and personal support worker teams, Dilico's Instagram and Facebook social media

websites (Appendix A), community presentations held by Dilico within First Nation communities, and one presentation at a 55+ gathering hosted by a First Nation community. The presentations, tailored to elders, shared details about the study and invited individuals to register. At the request of the Dilico community advisory committee, I also shared psychoeducation on dementia and printed materials from the Alzheimer's Society of Canada. During recruitment, the study was explained to individuals verbally and with a printed information letter (Appendix B). A research assistant and I also met with regional primary care providers, the cultural health team, and personal support workers to discuss the study and invite them to help identify and refer knowledge collaborators interested in participating. A script was provided to healthcare providers to assist with this process (Appendix C). Individuals registered for the study in person, via email, and by phone.

To meet the criteria for the study, knowledge collaborators had to be 18+ years of age, self-identify as FNMI, reside in Northwestern Ontario, be able to provide consent or have a legal decision maker, and read/speak English. Knowledge collaborators self-selected to attend an interview or a knowledge-gathering circle. Knowledge collaborators were provided with a $75 Mastercard gift card honorarium, a meal, and semaa (tobacco) offerings, if appropriate, to show acknowledgement of the relationship and respect for the knowledge shared (Kovach, 2009). Knowledge collaborators who attended an interview received an additional $30 Mastercard gift card instead of a meal. The Lakehead University Human Research Ethics Board approved this study (1470750).

**Assessing Incapacity to Consent.** Special recruitment considerations for conducting research with elders and people living with dementia were made. Research with people living with dementia tends to include an assessment of decision-making incapacity prior to obtaining

informed consent. However, this approach raises several practical concerns. First, existing approaches and measures for assessing incapacity solely evaluate cognition, ignoring that individuals may make decisions intuitively, emotionally, or spiritually (O'Connor, 2010). Second, existing approaches and tools do not draw on a relational perspective despite evidence that performance, behaviour, and capacity can fluctuate depending on the social context (e.g., interactions with the assessor) (O'Connor, 2010). Third, standard tools for assessing incapacity (e.g., Mini-Mental State Examination) have demonstrated inconsistent results in predicting capacity (e.g., O'Connor, 2010). Lastly, existing approaches to assessing incapacity may also be culturally unsafe. In research conducted in Australia with Aboriginal peoples, participants noted that impaired decision-making incapacity was not a culturally relevant concept (Clapton et al., 2011). In cases where it was understood, participants noted that impaired incapacity was not seen as a concern unless it was causing harm. Further, existing capacity assessments and processes were considered inadequate and flawed due to cultural bias (Clapton et al., 2011). Researchers have questioned the cultural relevance of the construct of impaired decision-making incapacity and have called on protocols and assessments to determine decision-making incapacity that ensure cultural aspects of competency are considered (Clements et al., 2010).

There is no published literature on assessing decision-making incapacity among FNMI people in a culturally safe way. Indigenous researchers stress that researchers interested in conducting research with Indigenous Peoples should respect and acknowledge community and culture-based internal mechanisms of determining whether individuals have information relevant to a study, who in the community is authorized and informed to share this information, and what information is appropriate (e.g., Baskin, 2005). Accordingly, I worked with Dilico to determine a culturally safe approach to determining decision-making incapacity.

When healthcare professionals invited potential participants to the study, they sought to identify and encourage people who do not have severe memory loss or who have an identified legal decision-maker. The registration form asked if the knowledge collaborators usually require assistance from a family member or other person to make healthcare or research decisions (i.e., a legal decision maker). If they replied yes, the form asked the participants to invite the care partner to the knowledge-gathering circle or interview and asked their legal decision-maker to provide signed informed consent. I also intended to obtain assent during data collection from the knowledge collaborator (Appendix D). Ultimately, all knowledge collaborators were considered capable of providing informed consent.

**Gathering Stories.** Demographic information was obtained through a questionnaire (Appendix E). Qualitative data were collected through four in-person knowledge-gathering circles and one-on-one and two-on-one semi-structured in-person and virtual interviews. Virtual interviews were held over Zoom (https://www.zoom.us/). When requested, I worked with Dilico and communities to coordinate transportation for knowledge collaborators to attend knowledge-gathering circles and in-person interviews.

***Knowledge Gathering Circles and Conversation Style Interviews.*** The design of the knowledge-gathering circles and interviews was informed by the intention to promote brain health, biskaabiiyang, good relationships, and transformative learning. I aimed to create spaces that reflected relational supports for aging in FNMI communities, including social connection, cultural safety, healthy eating, and dementia psychoeducation. My engagement with Dilico and local Elders was foundational to aligning the process with these values.

Knowledge gathering circles and interviews were held across Northwestern Ontario, including a large urban centre (population >100,000), a small town (<1,500), two road-connected

rural First Nation communities, and one rural First Nation community adjacent to the urban centre. Two planned gatherings were cancelled due to weather and venue limitations. The Dilico community advisory committee recommended the locations for knowledge-gathering circles.

The Dilico community advisory committee shared that each community has considerable diversity in cultural beliefs and practices. They recommended avoiding the term sharing circles to ensure inclusivity of knowledge collaborators who may not strongly identify with FNMI traditional beliefs. Elders also shared that the act of recording the circles did not align with the spirit or intention of a traditional sharing circle in this region.

I collaborated with cultural health workers and Elders from each community to respectfully determine the approach to each knowledge-gathering circle. This ensured that the cultural protocols of the region were followed. Dilico's cultural health workers helped to support these efforts by identifying Elders in each community to help lead the circle, assist with planning the gathering, and support the Elders at each circle. The cultural health team workers were provided gifts to honour their contributions. Elders were provided with an honorarium or gift and semaa.

Each knowledge-gathering circle started with a feast, which was catered by First Nation companies and featured brain health-promoting foods (e.g., berries) where possible. While often a component of cultural protocols, the feast also provided time to build rapport with knowledge collaborators. Moreover, I scheduled the knowledge-gathering circle times with consideration of participant preferences (e.g., mealtimes) and accessibility considerations relevant to elders (Mehta, 2011). Elders in each community opened and closed the circles in observance of local cultural protocols, including prayers, smudging, singing, and drumming.

Knowledge collaborators were advised that the purpose of the knowledge-gathering circle was to understand aging perspectives and local supports to facilitate healthy aging. I verbally

reviewed the letter of information and questions using a script (Appendix F). Oral consent was obtained as a group and documented using the oral consent log. Knowledge collaborators were invited to speak about their stories, perspectives, and experiences with dementia, risk reduction, assessment, post-diagnosis care, and relational supports that support care. Each knowledge collaborator was provided as much time as needed without interruption. After hearing from the perspectives of all knowledge gathering circle attendees, knowledge collaborators were invited to share any remaining thoughts. Knowledge-gathering circles were recorded with an audio recorder. Knowledge gathering circles occurred from March to April 2025. Knowledge-gathering circles, excluding the meal period and breaks, ranged from approximately 1 hour and 30 minutes to 2 hours and 25 minutes.

Two-on-one and one-on-one interviews were also conducted using a conversation-style approach. Kovach (2010) described the conversation method as “a dialogic approach to gathering knowledge that is built upon an Indigenous relational tradition” that utilizes “open-ended, semi-structured interview questions to prompt conversation where participant and researcher co-create knowledge” (p. 44). Despite concerns within mainstream research on building relationships as a form of coercion, Indigenous researchers have emphasized relationship building as a strength of the consent process (e.g., Peltier et al., 2024). Accordingly, I shared details about myself, intentionally used stories and humour to build rapport, and shared my relevant perspectives and experiences where appropriate. A script was used to guide the interviews (Appendix G). Interviews ranged from 2 hours and 17 minutes to 26 minutes and were recorded with an audio recorder. Knowledge collaborators who attended an interview were offered the opportunity to review and revise their transcripts.

I developed the interview and knowledge gathering circle questions (Appendix H) in consultation with the Dilico community advisory committee to ensure cultural and community relevance and appropriateness and to invite stories. I sought to begin with less sensitive information to help build rapport (Tachine et al., 2016). I also sought to style questions so participants could speak about others in their lives, allowing knowledge collaborators to discuss their views without feeling pressured to disclose personal experiences beyond their comfort level (e.g., Jones et al., 2020). Additional questions were developed organically during interviews and the knowledge-gathering circles.

During the knowledge-gathering circles and interviews, I also sought to share knowledge on brain health with knowledge collaborators. This initiative was to practice reciprocity while honouring my intentions for the research process and outcomes to promote brain health and transformative learning. Knowledge collaborators were provided resources on dementia risk reduction, assessment, and post-diagnosis care (https://www.i-caare.ca/dementia-factsheets; https://www.nccih.ca/Publications/Lists/Publications/Attachments/10385/Alzheimers-Disease-and-Related%20Dementias-in-Indigenous-Populations_Web_2022-08-11.pdf; https://alzheimer.ca/en/help-support/dementia-resources/national-resource-library). I also worked with a dietitian at Dilico to develop a booklet on traditional foods and recipes for brain health, which was also provided to knowledge collaborators. Additional copies of all resources were provided to Dilico regional offices during the community visits.

***Modified Photovoice Approach.*** A modified photovoice approach was used in the interviews and knowledge-gathering circles. Photovoice is an arts-based approach commonly used within community-based research that invites knowledge collaborators to take and share photos that represent their lived experience about a research topic (Hergenrather et al., 2009;

Pace, 2020; Wang & Burris, 1997). Photovoice approaches produce rich visual data and invite narratives and storytelling while highlighting community strengths and challenges to foster social change (Pace, 2020). Traditionally, photovoice approaches include a training session and provision of equipment (e.g., digital cameras) to knowledge collaborators. The current project utilized a modified photovoice approach to encourage visual storytelling and foster knowledge mobilization efforts. Knowledge collaborators were invited to provide an image or an object by emailing it to the research team or providing it in person, that represented something that promotes brain health during aging. Knowledge collaborators were not required to provide an image or object if they could not do so for any reason. Consent was obtained to share the images and objects publicly.

***Additional Considerations for Data Collection with Elders.*** Knowledge collaborators with cognitive impairment may experience difficulties with attention, comprehension, language, and memory (e.g., Jones et al., 2020). Focus groups with participants with cognitive decline can delay progress in the focus group and cause frustration for others (e.g., Jones et al., 2020). Difficulties articulating oneself can, in rare cases, cause the individual to feel frustrated, irritated, and aggressive (e.g., Jones et al., 2020). Moreover, memory difficulties can lead participants to forget questions rapidly. To address these potential concerns, I 1) shared the interview/knowledge-gathering circle questions with knowledge collaborators in advance where possible; 2) provided visuals (e.g., print-outs) of the questions; 3) limited the number of questions; 4) permitted and encouraged the involvement of care partners within interviews and knowledge gathering circles, which has shown to alleviate communicative and cognitive deficits; 5) offered breaks; and 5) held knowledge gathering circles earlier in the day in familiar locations to minimize physical and cognitive fatigue.

**Transcription.** All knowledge-gathering circles and interviews were transcribed using Vibe (https://thewh1teagle.github.io/vibe/). A research assistant and I reviewed the transcriptions for accuracy and to remove identifying information. Knowledge collaborators selected their pseudonyms.

**Reflexive Thematic Analysis.** Qualitative and visual data were analyzed using NVivo (Version 12) (https://lumivero.com/products/nvivo/) and Braun & Clarke's (2006) six steps of reflexive thematic analysis. Thematic analysis is a method to systematically examine, identify, and organize qualitative data to identify shared meanings and experiences across the data set relevant to a research question (Braun & Clarke, 2006). Thematic analysis was an appropriate method for the current study due to its methodological flexibility, allowing for diverse ontological and epistemological assumptions without violating the foundational premises of the approach (Braun & Clarke, 2006). Several approaches to thematic analysis exist along a spectrum of post-positivist to constructivist assumptions (Braun & Clarke, 2022). Constructivist orientations, which do not emphasize neutrality or objectivity, align more with a Nishnaabeg relational ontology. Aligned with a relational ontological position, reflexive thematic analysis emphasizes that researcher subjectivity is a core tool for deriving meaning from the analysis (Braun & Clarke, 2022). Reflexive analysis invites researchers to reflect on and interpret the meanings of the data and encourages collaborative meaning-making (Braun & Clarke, 2022), which is aligned with a relational epistemological position.

I used a deductive and inductive approach to identify latent and semantic themes. A deductive orientation to reflexive thematic analysis involves utilizing a pre-existing theory to help understand the data (e.g., Braun & Clarke, 2022). In comparison, researchers utilizing an inductive orientation solely draw meaning from the data and their interpretations (e.g., Braun and

Clarke, 2022). Braun and Clarke (2006; 2022) emphasize that researchers can utilize deductive and inductive orientations. I used a mixed approach in the present study. Reflexive thematic analysis can also utilize latent (e.g., implicit) and/or semantic (e.g., explicit) coding to interpret the data set (e.g., Braun & Clarke, 2006). I utilized both approaches to examine explicit and latent meanings. I conducted all coding and have previous experience with reflexive thematic analysis within FNMI community-engaged participatory research.

I examined the qualitative data and visual images to 1) identify common themes relating to perspectives of the meaning of dementia symptoms, risk reduction, assessment, and post-diagnosis care and 2) identify individual-level, interpersonal-level, and community-level relational supports that facilitate risk reduction, assessment, and post-diagnosis care. First, I reviewed the transcripts multiple times and reflected on initial ideas and commonalities. Second, I conducted open coding of the data with consideration of the research objectives. Third, I collated the codes, reviewed their content, and organized them into subthemes and broader themes. Following Braun and Clarke's (2006) definition, a theme captures "something important about the data about the research question and represents some level of patterned response or meaning within the data set" (p. 82). At this stage, I conducted a sub-analysis of codes and preliminary themes to examine the influence of gender and geographical location. I examined the coded extracts according to these knowledge collaborator characteristics to determine whether the content varied within or across groups, and whether any codes were specific to identities or locations. Next, I reviewed the coded extracts of each potential theme and subtheme, if applicable, to ensure internal homogeneity, and the themes were compared to ensure external heterogeneity. The themes were reviewed against the entire dataset to ensure validity. Finally, I developed titles that reflected the overall meaning of each theme.

**Methodological Integrity.** To ensure methodological integrity, analysis and interpretation were guided by the community advisory committee. Moreover, I engaged in reflexivity throughout the project through voice journaling and discussions in supervision meetings (Johnson & Waterfield, 2004). Feedback on the research approach was elicited from knowledge collaborators at the end of the interviews and knowledge-gathering circles to evaluate the research approach. All methodological decisions were documented to improve transparency. The community advisory committee guided analysis and interpretation as a form of member checking (Johnson & Waterfield, 2004). For instance, the initial themes were shared with the community advisory committee for feedback and validation. To further substantiate member checking, I shared our initial results with the knowledge collaborators and sought feedback before finalizing the results. I also elicited feedback from the community advisory committee to assess the usefulness of the results. Lastly, I sought feedback from the community advisory committee on improving the methodological approach for future research studies.

## Results

Knowledge collaborator demographics are included in Table 1. Data on interview and knowledge gathering attendance are included in Table 2.

**Table 1**

*Knowledge Collaborator Demographic Information and Relationship to People Living with Dementia*

| | | Knowledge collaborators (*n* = 42) |
|---|---|---|
| Mean age (SD) | | 59 (*SD* = 16.02)<br>Range: 26 - 87 |
| Gender (%) | Man | 11 (26.19%) |
| | Woman | 29 (69.05%) |
| | Two-Spirit | 2 (4.76%) |
| Sex (%) | Male | 12 (28.57%) |
| | Female | 30 (71.43%) |
| | Intersex | 0 (0.00%) |
| First Nations or Métis identity (%) | First Nations | 38 (90.48%) |
| | Métis | 1 (2.38%) |
| | Non-FNMI (spouses) | 3 (7.14%) |
| Employment (multi-select) | Employed (full-time/part-time/self) | 9 |
| | Stay-at-home parent or grandparent | 3 |
| | Unemployed | 3 |
| | Disability | 8 |
| | Retired | 16 |
| | Student/other/don't know/no response | 3 |
| Annual household income (%) | <10,000 | 1 (2.38%) |
| | 10,001-20,000 | 7 (16.67%) |
| | 20,001-30,000 | 5 (11.90%) |
| | 30,001-40,000 | 5 (11.90%) |
| | 40,001-50,000 | 2 (4.76%) |
| | 50,001-60,000 | 5 (12%) |
| | 60,001-70,000 | 1 (2.38%) |
| | >70,000 | 4 (9.52%) |
| | Don't know/no response | 12 (28.57%) |
| Highest level of education (%) | Some elementary school | 1 (2.38%) |
| | Elementary school | 6 (14.29%) |
| | Some high school | 5 (11.90%) |
| | High school diploma or equivalent | 5 (11.90%) |
| | Some college/university | 5 (11.90%) |

**Table 1 (continued)**

| | | Knowledge collaborators (*n* = 42) |
|---|---|---|
| Highest level of education (%) | College diploma | 8 (19.05%) |
| | University degree | 3 (7.14%) |
| | Graduate or professional degree | 2 (4.76%) |
| | Other | 2 (4.76%) |
| | Don't know/no response | 5 (11.90%) |
| Geographical location of residence (%) | Urban or suburban | 15 (38.09%) |
| | Rural | 26 (61.90%) |
| On-reserve residence (%) | On-reserve | 22 (52.38%) |
| | Off-reserve | 20 (47.62%) |
| Relationship to a person living with dementia (multi-select) | My spouse/partner | 2 |
| | My parent(s) | 6 |
| | Extended family member(s) | 19 |
| | Friend(s), neighbour(s), or colleague(s) from work | 12 |
| | Community member(s) | 4 |
| | Elder(s) and/or Knowledge Keeper(s) | |
| | No one | 6 |
| | Don't know/no response | 5 |

**Table 2**

*Data on Interview and Knowledge Gathering Attendance by Location Type*

| Data collection approach | Location type | Knowledge collaborators |
|---|---|---|
| One-on-one interview | Urban and rural | 14 |
| Two-on-one interview | Urban and rural | 10 |
| Knowledge gathering circle | Community 1 - rural | 2 |
| | Community 2 – rural | 4 |
| | Community 3 – rural | 9 |
| | Community 4 - urban | 3 |

Qualitative data were engaged to explore the meaning of dementia symptoms; approaches to reducing risk, assessment, and post-diagnosis care; individual, interpersonal, and community relational supports related to dementia care; and the influence of FNMI identity, gender identity, and geographical location on these perspectives. Notably, given the absence of Inuit knowledge

collaborators and limited Métis knowledge collaborators in this study, the results should be best interpreted as a description of First Nation perspectives.

I constructed 14 themes using thematic analysis across four sections (the meaning of memory loss, risk reduction, assessment, and post-diagnosis care). The following themes reflect cultural perspectives of the meaning of dementia symptoms, risk reduction, assessment, and post-diagnosis care, relational supports, and the influence of gender identity and geographical location. A summary of the 14 themes is illustrated in Table 3. Individual, interpersonal, and community-level relational supports are further illustrated in Tables 4, 5, and 6, respectively. Photovoice images from 10 knowledge collaborators used in the data analysis are presented as a figure in Appendix I. Photos have not been listed with the qualitative data to protect the identity of knowledge collaborators.

**Table 3**

*Summary of the 14 Constructed Themes and Subthemes by Content Area*

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Meaning of dementia symptoms | The meaning of dementia symptoms | Emerging understandings of dementia in Northwestern Ontario | Dementia was absent or rare in First Nations communities. Knowledge collaborators described an increasing number of people living with dementia in their communities. This increase has prompted fear and worry, and an awareness of the need for more education on dementia. | "I spoke to a lot of elders, especially our relatives, when I talked about how old they are, they never talk about things like this happening. We didn't even know that was happening to people". |
| Risk factors and reduction | Dementia risk across the lifespan: A wholistic view of determin-ants | Individual, interpersonal, and societal factors increase risk across the lifespan (individual, interpersonal, societal) | Age, genetics, physical health conditions, mental and emotional distress, social isolation, lack of accessible healthcare, pollution, and disruption to First Nation ways of being are risk factors for dementia. | "Even in [reserve], there was this notice a couple of years ago, or even last summer, that there was too much mercury in the fish. With the food costs right now, it's cheaper to eat out at McDonald's than it is to buy a salad at the store". |
| Risk factors and reduction | Reducing the risk of dementia by aging well | Caring for our whole selves | Caring for mental, emotional, physical, and spiritual wellness helps to address identified dementia risk factors. | "My aunt used to tell me stories about her mom. She didn't have dementia (…). All they did was eat wild food when she was growing up. That's what made her live longer. And she drank cedar water. She said they used to go hunting, and she still remembers. She's 89 years old, and she still has good memory". |

**Table 3 (continued)**

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Risk factors and reduction | Reducing the risk of dementia by aging well | Local and virtual wraparound care services | Access to local and virtual culturally safe services to support health, community-based programs (e.g., bingo), community-based health fairs, home cleaning, community and home gardens, and transportation services helps address risk factors. | "That was the first time I went out in three weeks is when I did that [gathering held by local First Nations-led health organization] thing. I barely leave my house, so it's hard for me to make any connections". |
| Risk factors and reduction | Reducing the risk of dementia by aging well | Aging well is relational: Strong kinship networks, strong aging mind | Connected and supportive families, partners, and friends, and connection to land, help to address dementia risk factors through supporting social connection, support, belonging, physical activity, and health monitoring, among other outcomes. | "I have two sisters, and I adore them. I am so grateful for what they do for me. There are times where I can't get up off the floor, mentally, not physically, but you know, just contact with them. I'm right back at it again, and I'm grateful for that. I need them". |
| Risk factors and reduction | Reducing the risk of dementia by aging well | Cultural continuity through intergenerat-ional relationships supports aging well across the lifespan | Relationships between elders and youth facilitate reciprocal wellness through transmitting knowledge on substance use, supporting cultural identity and goal development, and fostering a sense of purpose. | "Now that I am retired, I'm doing a job I love that feeds my spirit. When I'm going into the schools to spend time with children, that is the highlight of my day. I look forward to that and I can't wait to get to bed and wake up in the morning to get there so I can see their smiling faces and sing with them (…). It helps me age well, too. |

**Table 3 (continued)**

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Risk factors and reduction | Reducing the risk of dementia by aging well | Using our gifts in the community | Opportunities for community involvement in helping roles, such as teaching others and developing and leading programs, help to promote a sense of purpose, spiritual wellness, social connection, and a community of care. Several values, including reciprocity and respect, facilitated a desire to help others in the community. | "If we get a moose, a big moose, we share it with the people on the reserve. The elders. And give them a piece, [so they] can make some stew". |
| Assessment | Wholistic assessment of dementia | Families and healthcare providers support loved ones on their assessment journey | Family members are typically the first to notice changes in a loved one's socialization, emotion, cognition, and behaviours, and support the loved one in obtaining an assessment from a healthcare professional. Dementia health literacy (e.g., awareness of early symptoms) facilitated earlier detection. | "I got him checked out, and we went to see a doctor. That is when they were saying yeah, there he's got something wrong with him, dementia". |

**Table 3 (continued)**

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Assessment | Wholistic assessment of dementia | Dementia influences the whole self | Knowledge collaborators noticed changes to their loved ones' socialization (e.g., social isolation), cognition (e.g., forgetting, personality changes, hallucinations, "going back in time"), behaviour, and emotions. Changes to the spirit were not described. Aligned with a relational identity, contextual factors and relationships influenced symptom course and severity. | "He'll constantly ask for his wife, even though his wife passed away. He would be like he was a kid again. Like "I'm going to go out and play". |
| Post-diagnosis care | Caring for loved ones living with dementia | Wraparound care honours loved ones' wishes to age in place | Family members and their loved ones living with dementia prefer to age in place, often in rural First Nation communities. This desire is supported by supportive family members, community members, and paid care partners (e.g., personal support workers). Local long-term care supports aging in place when symptoms become too severe for family members to manage. | "They have workers going in for home care for her, because [her husband] works out of town for two weeks at a time, and then he comes home for two weeks. She gets that care for personal support at home care, and her sister lives across the road, so they go and check up on her". |

**Table 3 (continued)**

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Post-diagnosis care | Caring for loved ones living with dementia | Culturally safe dementia healthcare | Access to culturally safe care (e.g., cultural activities, First Nation ways of being in caregiving relationships, and a distinctions-based approach) supports a sense of purpose, meaning, belonging, memory recollection and improves symptom severity. | “I'll do visits with them, or we bring them together to do like we do once a month drumming. So, we'll get them together to do that kind of thing. We had a sacred fire in September. (…). Oftentimes, it's their reality, and they're there. For me, it doesn't feel like it's someone that's living with dementia, whereas I'll go and read their chart, or I'll hear, like, oh, this happens. And then I'm like, oh, I've never seen that side of that person”. |
| Post-diagnosis care | Caring for loved ones living with dementia | Caring for care partners | Despite cultural values supporting care from family members, care partners experience distress associated with caring for a loved one living with dementia. Knowledge collaborators emphasized the need for respite and support from extended family members. | “When [my friend] spoke about dementia, I thought, "Oh god, I better be prepared." Because naturally, with us women, with the [First Nation] women up there, it fell on the women to provide for their parents”. |

**Table 3 (continued)**

| Content Area | Title | Themes (subthemes) | Description | Supporting quote |
|---|---|---|---|---|
| Post-diagnosis care | Caring for loved ones living with dementia | Honouring wise practices and expanding knowledge for relational dementia care | Supporting autonomy, joining the person's reality, using humour and memory cues, providing person-centred and continuous care, implementing alarm systems, speaking FNMI languages, and accepting the loved one with dementia all help facilitate effective care. Despite the existence of wise practices, additional psychoeducation is needed to support care partners better. | “He loved talking about setting the net. He would say, "I'm setting the net. You guys want fish?" We would all say yes. Even the nurses had to say, “Yes, we love fish”. He said, "I'm setting it, and I'm going to be back in the morning with fish." |
| Post-diagnosis care | Caring for loved ones living with dementia | Connection to kinship networks | Social connection (e.g., visiting with family and friends, social programs) and connection to land (e.g., fishing, sacred fires) help support a sense of belonging and reduce social isolation and symptom severity among people with dementia. | “I used to take her [a loved one living with dementia living in the hospital] blueberries, break them off, and I let her pick, and she can eat it. So, when I took these blueberries, pretend you are picking blueberries”. |

**Table 4**

*Individual-Level Relational Supports in Northwestern Ontario to Support Dementia Risk Reduction, Assessment, and Post-diagnosis Care*

| Relational Support | Description | Availability | Notes | Supporting Quote |
|---|---|---|---|---|
| Cultural identity | Connection to cultural identity, items, and traditions facilitates physical activity, healthy eating, social connection, mental (e.g., sense of purpose) and emotional wellness (e.g., healing from trauma). | Rural and urban | Present in all communities. | "That's who taught me who I was as a Nishinaabe. Who I was to help me dig out all that what I carried, what wasn't mine. Taught me how to let it go, release it, let it out, let it be heard. It was my Nishinaabe way that helped me heal and that's why I brought this drum. That's why I wanted to say, this is who I am as a Nishinaabe". |
| Dementia health literacy | Knowledge about the signs and symptoms of dementia, approaches to risk reduction, and care. Knowledge is obtained through family members and friends with experience supporting others with dementia; there is limited mention of external education. | Rural and urban | Somewhat more limited in rural communities. | "Made coffee, didn't put water in the pot one day. Made coffee, didn't put coffee in the thing. So little things that was all recognized. I used to tell her that's what my dad [who lived with dementia] used to do". |
| Technology access | Access to mobile phones, laptops, and computers. Provides access to virtual healthcare, social connection, and cognitive stimulation (e.g., online puzzles). | Rural and urban | More limited in rural communities. Requires technology literacy. | "So, a lot of times, I am doing my crossword puzzles on the computer". |

**Table 4 (continued)**

| Relational Support | Description | Availability | Notes | Supporting Quote |
|---|---|---|---|---|
| Financial support | Monthly payment to seniors from the Band. | Community-specific | Mentioned by one knowledge collaborator | "[First Nation Community] gives us $200 a month to help, which is really good. Other bands don't do that. But I think it was pushed by some, a few of the older ones on band council many years ago". |
| Connection to land | Connection to land and waters (e.g., through land-based activities). | Rural and urban | Access may be limited due to pollution. Activities sometimes depend on equipment access. | "I think, like for my dad, what helped him was being able to get out on the land. You know, going fishing or going hunting or whatever. Him and my husband went out pretty well every weekend when the kids were young". |
| Roles for retired elders in the community | Roles in the community, including traditional roles, for elders, including those who have retired from formal work | Rural and urban | Opportunities may be limited in some communities. | "Me and my son, we started a land-based cultural program out in the country, and it's beautiful. We've served over 4,000 people so far, especially young people. We start them off on their path of learning about the Anishinaabe way. I've lived, despite my impediments, I've lived a pretty and worthwhile life, using myself and my knowledge and whatever to make things better for our people. So, I have not retired". |

**Table 5**

*Interpersonal-Level Relational Supports in Northwestern Ontario to Support Dementia Risk Reduction, Assessment, and Post-Diagnosis Care*

| Relational Support | Description | Availability | Notes | Supporting Quote |
|---|---|---|---|---|
| Connected families | Family members help to identify symptoms, support dementia health literacy, support wholistic wellness, and care for loved ones living with dementia (e.g., meal preparation and feeding), including those living in long-term care. | Rural and urban | Reliant on supportive and available family members, and the extent of existing responsibilities. Less available in more rural communities. Women are more likely to be the primary care partner. | "Everybody would just come, and we all took turns, like every family took turns taking care of our grandmother, and then just listening to everybody say, Oh, you keep her for this amount of time, then when you're done, we'll take her". |
| Connected communities | Knowledge collaborators support wholistic wellness, sharing food and meals, safety, social support, and supporting home maintenance. | Rural and urban | Most frequently mentioned in rural communities. | "One day, [redacted] had that off day, and everybody knew that. Everybody was like, "Okay, we've got to watch after [Redacted]." It's a good community that keeps an eye on one another". |
| Cultural values to support helping | Cultural values underlie helping behaviours, including respect for elders, reciprocity, autonomy, and love. | Rural and urban | | "Respect for elders, the fact that I have to be very respectful to my elders and they have to make me realize that once in a time I'm going to get to this age. So, I have to try as much as possible to treat them the way I want to be treated when I'm there". |

**Table 5 (continued)**

| Relational Support | Description | Availability | Notes | Supporting Quote |
|---|---|---|---|---|
| Informal peer support networks | Informal peer support networks provide social support and share information on dementia and other age-related conditions. | Rural and urban | It may be more widely available, but not freely mentioned by knowledge collaborators | "Are you going to get depressed because you forgot that your toast is in the toaster? No, you've got to laugh it at. When I'm out with people my age, we're in the same boat and we laugh louder". |
| Intergenerational relationships with youth and elders | Intergenerational relationships support cultural identity development, goal development, education, and mental, emotional, physical, and spiritual wellness for Elders and youth. | Rural and urban | It may require programs to facilitate connections. | "[My grandmother] always had really wise words, and the biggest word that is very simple. "Mano" means leave it. Leave it. Leave it. You know when people talk about you or whatever? Mano". |
| Healthcare professionals and staff with training in dementia | Healthcare providers and professionals who have received training or education on providing care to people living with dementia. | Urban | It may be limited in rural communities. | "[The resident] was looking out the window and she was like, oh my gosh, like, do you see, like so and so outside, and I was just like oh, what? So, I looked outside and there was no one there. At that point it was either like okay, do I play along, or do I like say no and I was like well, whatever, this is this is her reality". |

**Table 5 (continued)**

| Relational Support | Description | Availability | Notes | Supporting Quote |
|---|---|---|---|---|
| Healthcare professionals and staff with training on culturally safe care | Healthcare professionals and workers with knowledge and training on providing culturally safe care, including care for people with dementia. | Rural and urban | It may be limited in rural communities. | "He was so involved in this community, but then he didn't usually want to come down to drumming or like any of those events. So, I was just kind of like okay, like it's, whether it's the institution or his dementia. I was like, okay, this is the new reality and we're not going to try and push anything on him because that's what happened at one point [at residential schools]". |
| Family and community care partners with dementia health literacy | Care partners with knowledge, education and/or training on identifying dementia symptoms and providing post-diagnosis care. | Rural and urban | It may be limited in rural communities. | "They told me how in order to me to validate her feelings that I should acknowledge the fact that the emotions are going to switch. And even if I don't agree with the person, even if I don't agree with my perspective, I have to try as much as possible to respond to them." |

**Table 6**

*Community-Level Relational Supports in Northwestern Ontario to Support Dementia Risk Reduction, Assessment, and Post-diagnosis Care*

| Relational Support | Description | Availability | Notes | Quote |
|---|---|---|---|---|
| Community-based programs: City | Programs and organizations supporting social and physical health include the 55+ centre, community centres, and urban Indigenous programs (e.g., drum groups). | Urban | It may be limited for rural knowledge collaborators due to transportation barriers. | "You know, just watching TV, lying around watching TV, and not eating properly isn't going to help you age well. But if you're having these social connections, like a drum group or other social-type groups, it might get you out of the home. You're going to have something to live for and look forward to". |
| Community-based programs: First Nation Community | Language programs, powwows, and social events for seniors (e.g., Bingo). | Rural | It may be limited in some rural communities. | "It keeps the brain going here. We come to the bingo's". |
| First Nation-led health organizations | The organization provides monthly events for older adults, cultural programs, mental health services, in-home care support, travelling healthcare services, transportation, health liaison services, culture-based substance use treatment, traditional medicines. | Rural and urban | It may be limited by staff availability. | "We have the [organization] coming there every month. I think that's helping us to look after our health too". |

**Table 6 (continued)**

| Relational Support | Description | Availability | Notes | Quote |
|---|---|---|---|---|
| On-reserve band-managed health services | Provides in-home support, including personal support workers, homemakers, and nurses | Rural | It may be limited by staff availability. Services for off-reserve members may be restricted. | “Here they do have community support, but it's all limited based on the staffing and how many clientele and the ratio”. |
| Local long-term care and other residential care | Long-term care, assisted living, and cooperative housing facilities provide residential care to people living with dementia. | Urban | It may be limited by waitlist and costs. Rural knowledge collaborators are required to travel. | “My brother, who's 86, given with his complex health issues, he needs to be in long-term care for his well-being and his safety. There's an eight-year waitlist”. |
| Culturally safe long-term care | Provides culture-based and distinctions-based care for FNMI residents, including monthly drumming, land-based programs, virtual visits, language speakers, therapeutic recreationists, physiotherapists, and spiritual support. | Urban | Available for rural residents, but must move, at times, several hours away. | “I get [my residents] together. I'll do visits with them, or we bring them together, like we do once a month drumming. So, we'll get them together to do that kind of thing. We had a sacred fire in September”. |

**Table 6 (continued)**

| Relational Support | Description | Availability | Notes | Quote |
|---|---|---|---|---|
| Local and travelling healthcare services | Healthcare services to support adults and elders, including personal support workers, homemakers, mental health counselling, geriatricians, psychologists, care navigators, social workers, occupational therapists, registered practical nurses, and nurse practitioners. | Rural and urban | Limited availability in rural communities. | “My husband and I don't have a doctor; we use a nurse practitioner. He comes and they monitor us, and that's what helps with our diabetes”. |
| Respite programs | Respite programs to support care partners of people living with dementia, including funding to support low-income care partners. | Rural and urban | It may be more limited in rural communities. | “I'm getting help, you know, I'm getting help from a place called, you know, that place there, well, they give me money, eh? So, I can have a respite”. |
| Community health fairs | Improves dementia health literacy. | Rural | Unclear whether this relational support is available within an urban environment. | “I was at the health fair, and this lady was there talking about Alzheimer's. And I said, "Can I ask you a question?" And I said, "What are the signs of Alzheimer's?" Because I seem to be forgetting I'm writing something, and I'll forget what I'm writing”. |

**Table 6 (continued)**

| Relational Support | Description | Availability | Notes | Quote |
|---|---|---|---|---|
| Telehealth | Virtual care for mental health services. | Rural and urban | Requires access to technology and technology literacy. | "I've seen [the psychiatrist] in [town]. They're at the clinic on TV. I see him, every second month or first month". |
| Dementia continuing education programs for healthcare professionals and workers | Virtual education programs, suited for northern and FNMI communities, for healthcare providers. | Rural and urban | Mentioned by one community member. Education programs for FNMI populations and northern communities may be limited. | "I'm doing a course with the Center for Education Research and Health. It's looking at Indigenous perspectives on aging and end of life". |
| Psychoeducation programs for community members | Provides information on dementia signs and symptoms, risk reduction, and post-diagnosis care (e.g., communication strategies). | Rural and urban | Mentioned by two knowledge collaborators. May be limited to absent in some rural communities. | "We don't have an Alzheimer's Society out here, but we know it's in town. If we need access, we have easy access". |
| School programs for youth and elders | Programs to connect youth with elders. | Rural | Mentioned by two knowledge collaborators. | "I taught the grade five class to do beading. The education director required the teachers to do something with the kids after school. So then [the teacher] added that". |

**Table 6 (continued)**

| Relational Support | Description | Availability | Notes | Quote |
|---|---|---|---|---|
| Local and regional transportation services | Local and regional transportation services, including transportation services supported by local healthcare organizations, to assist adults with attending medical appointments and grocery shopping. | Rural and urban | Limited in some rural communities. | "They have this transport service that do come to our area most of the times to take elderly people to wherever they're going to, if you have appointment, you want to go to market, they help you without charging". |
| Spirituality and religious centres | Catholic and Pentecostal churches. | Rural and urban | | "Catholic church and a Pentecostal church. I go to both. [It helps me] with mood and relationships". |
| Water treatment plants in First Nation communities | Access to clean drinking water may support risk reduction. | Community-specific | Mentioned by one community member. | "[My family members] are the water operators here for our new water plant, and they got told that [First Nation community] has the best water here compared to even better than [city] and to [city]". |
| Land and waters | Accessible lakes, rivers, hiking trails, parks, crown land, and golf courses to facilitate physical, mental, emotional, and spiritual wellness. | Rural and urban | It may require transportation and equipment. | "I love going with my parents. I love going in the bush, because that's my connection with the earth". |

## The Meaning of Dementia Symptoms

### *Emerging Understandings of Dementia in Northwestern Ontario First Nation Communities*

Most knowledge collaborators shared that, while they could recall some instances of elders with some memory loss while growing up, they did not recall many instances of elders living with dementia. This is notable, as many First Nation communities are close and connected, and knowledge collaborators shared several instances of spending time with parents, grandparents, aunties, uncles, and other elders. For instance, Veronica (First Nations, woman, 82), who lives in a rural community, shared that dementia used to be uncommon in her community:

> I spoke to a lot of elders, especially our relatives, when I talked about how old they are, and they never talked about things like this [dementia] happening. We didn't even know that was happening to people.

This was echoed by knowledge collaborators who reside closer to an urban city. For instance, while discussing whether they could recall any community members living with dementia when they were growing up, Willow (non-FNMI, woman, 79) and Poplar (First Nations, man, 81) shared:

> Willow: There's an underlying common [belief], [the elderly person is] a little forgetful, it's part of who you are.
>
> Poplar: It's just so typical.
>
> Willow: You just accept it. It is what it is, but nobody was in danger of wandering or burning down the house because they forgot to put the stove off, and of that there was none.

Several knowledge collaborators shared how dementia was not discussed in the community and within families while growing up, and that community members are only recently starting to learn about dementia, often after having family members diagnosed by healthcare professionals.

Maggie (First Nations, woman, 79) shared that she first heard about dementia after her mother-in-law was diagnosed with Alzheimer's disease:

> I never heard that word [dementia] before my mother-in-law. Nobody never had that in that place [home community].

Given the oral tradition within First Nation communities of sharing stories and history across generations, the lack of awareness suggests that dementia was relatively uncommon. Despite these frequent experiences, some knowledge collaborators shared memories of grandparents living with dementia, but noted that this was not seen as a disease. Niin (First Nations, woman, 62), who provides care to a parent with dementia and who had a grandmother who lived with dementia, discussed how dementia was not viewed as a disease in her community when she was growing up:

> It wasn't anything to be pointed at her. It was just, "Yeah, we're getting old." They understood. The elders knew that getting old, you forget things. But it was never looked at like a disease, but much more for them, seeing her forgetting things or thinking other things that weren't at the time, like for shovelling [in the summer]. That's the one that really stands out a lot because it was a happy thing. It was a funny thing. It was a cute thing. If you met my Dudu [grandmother], you would have laughed with her with that. Not at her, with her.

In some cases, knowledge collaborators recalled stories of elders with memory loss and behaviour change, which may have been symptoms of dementia. However, they recalled that these symptoms were described by grandparents, parents, and other community members as "going back to a kid", "old age", "being nuts", "sick in the mind", "off her rocker", "not all

there", "old man's craziness" and "acting crazy". One knowledge collaborator shared that elders displaying symptoms of dementia were said to have "birch bark in their ear" from a "shaman".

One way to examine the historical presence of dementia among First Nation communities is to examine whether there is a language to name or describe the syndrome. While some Anishinaabemowin words were shared that described symptoms of dementia, such as forgetfulness, knowledge collaborators noted that these words did not necessarily reflect dementia and were likely used to describe everyday experiences. Moreover, Pine (First Nations, woman, 65) shared that "it's almost like you can't just say one word [to describe dementia], it has to be a whole bunch of words together". Some Anishinaabemowin words that were shared included "forgetting", "forgetful", "brain injury", "doesn't know", and "don't know". However, many knowledge collaborators shared that they do not speak the language fluently due to language loss associated with colonization, such as residential schools. The potential absence of a single word to fully describe dementia suggests that this may be a modern syndrome among First Nation communities in Northwestern Ontario.

Despite dementia being a relatively new syndrome in First Nation communities in Northwestern Ontario, most knowledge collaborators shared that they have noticed an increasing number of people living with dementia in their communities, and an increase in awareness of dementia as a result of a disease. For instance, Debbie (First Nations, woman, 73) shared how they have noticed more people living with dementia:

I didn't see this [dementia] as much in the past as I do now. I find it's more.

This suggests that dementia was either absent or less common in First Nation communities, but has become more apparent, perhaps due to an increased number of cases, longer life span, and/or additional psychoeducation and awareness.

The recognition of the increasing number of people living with dementia in First Nation communities in Northwestern Ontario was often paired with fear and worry, as dementia was described as a "scary disease" to be avoided. Knowledge collaborators also described a need for more accessible information to reduce risk better, assess, and care for loved ones living with dementia, including opportunities to gather and discuss dementia within the community. For instance, Darryl (First Nations, man, 59) shared:

> What's the beginning signs, what's the late stages of dementia? How are we going to know that, and how do we prevent, and how do we teach?

Knowledge collaborators shared that increased knowledge about dementia may lead to earlier diagnosis, a reduction of stigma, and improved care, highlighting the need for additional psychoeducation strategies directed to First Nation people and communities in Northwestern Ontario.

## Dementia Risk Across the Lifespan: A Wholistic View of Determinants

Knowledge collaborators described several factors that they believed may increase the risk of dementia. These risk factors reflected a wholistic perspective of dementia risk, including factors at the individual (e.g., advanced age and genetics, physical health history, and mental and emotional distress), interpersonal (e.g., social isolation), and societal (e.g., inaccessible healthcare services, disruption to First Nation ways of being, and pollution), levels.

### *Individual, Interpersonal, and Societal Factors Increase Risk Across the Lifespan*

**Individual.** Knowledge collaborators shared that increasing age and genetics are causes of the increased number of First Nations people living with dementia. For instance, when discussing the increase of dementia in First Nation communities, Nolan (First Nations, man, 47), whose loved one lives with dementia, shared:

> I think people are living longer. And I think just that longevity. I think of my Nana, who died when she was 63. If she had been alive until 93, there would have been an onset there, right?

This illustrates the influence of non-modifiable risk factors, including age and genetics, on the risk of developing dementia among First Nation Peoples in Northwestern Ontario.

Knowledge collaborators shared that several physical health conditions may increase the risk of dementia and speed of cognitive decline within First Nation communities, including diabetes, physical inactivity, head injuries, high blood pressure, vision and hearing loss, infections, Parkinson's Disease, stroke, and general poor health. In some cases, knowledge collaborators highlighted the reciprocal and interconnectedness of physical and cognitive health, and emphasized the importance of caring for the physical body to reduce the risk of dementia.

Knowledge collaborators expressed concern over the impact of mental and emotional distress on increasing the risk of dementia. They highlighted how a lack of cognitive stimulation and a sense of purpose or "reason for existing", and increased substance use (e.g., alcohol and tobacco), depression, grief, stress, and trauma may increase the risk of developing dementia. For instance, Pine shared that witnessing and enduring hardships within First Nation communities, such as addiction, and the loss of children from Residential Schools, illnesses, and accidents, may increase stress and grief, and increase the risk of developing dementia. Other causes of stress and trauma discussed among knowledge collaborators included adverse childhood experiences (e.g., "raised up from a broken family"), physical abuse in adulthood, increased workplace and family responsibilities, the death of a loved one, and not meeting perceived societal expectations. For instance, Veronica shared:

> Could it be the trauma that we suffered when we went to Residential School[s]? Could it be that we want to forget it? Because our elders, the ones we're talking about [who did not have dementia], they never went to school. My dad never went to school, and my aunties never went to school. So maybe it was after that, then my mom went to school. But the others, they never went, they didn't have that trauma to leave their families behind to go and grow up over there, that was without the parents. Maybe that's what they're trying to forget. Maybe that's why it's there.

Knowledge collaborators shared that when experiences of trauma, stress, and grief are coupled with a lack of social support and increased social isolation from family members, the risk may further increase, underscoring the interconnectedness of individual and interpersonal risk factors.

**Interpersonal.** Knowledge collaborators shared that social isolation may increase the risk and progression of dementia. For instance, Nicole (First Nations, woman, 26), who is a paid caregiver for FNMI people living with dementia, shared that she has observed a more rapid cognitive decline among residents who do not have any family, friends, or other visitors than among residents who do. This emphasizes the need for local residential care facilities, social programs in long-term care, and transportation for families to visit loved ones in long-term care. Daryl further emphasized the importance of intergenerational relationships in supporting brain health, highlighting how elders can share cultural knowledge and help reduce social isolation, which in turn supports their health and wellness:

> My uncle says, "I'm going to keep my granny busy. I'll keep her mind." And the Christians say you have to develop a relationship with the Supreme Being. And the Anishinaabe’s says you got the same. So, we must interact more and more with our elders. We can’t neglect them.

Knowledge collaborators also stressed that the decline or absence of social gatherings in their communities, especially gatherings for elders, may also contribute to social isolation and cognitive decline.

**Societal.** Knowledge collaborators shared that a lack of accessible healthcare may increase the risk of dementia. Knowledge collaborators described how some families faced barriers to accessing care, particularly those without access to a vehicle and who reside at large distances (e.g., >100 km) from major hospitals. A lack of assisted living or residential care facilities in some First Nation communities was also viewed as contributing to dementia risk through increasing social isolation. For instance, Willow shared:

> If we had a long-term care facility here, assisted living, where you're not ready for long-term care, but at least you have that social contact, which really is a preventative thing. If I'm in my own house, I'm living on my own, by myself, it's more likely that I would end up having dementia.

This suggests that increasing access to residential care and assisted living facilities, where connection with other elders is more likely, may help reduce dementia risk in First Nations communities in Northwestern Ontario. At the same time, knowledge collaborators also expressed concern about individuals from rural and remote areas being relocated several hours away from their community to access long-term care settings to access healthcare services, such as kidney dialysis, due to the lack of more local healthcare alternatives. The separation from their home community was seen as contributing to social isolation from friends and family and increasing the risk of cognitive decline.

Knowledge collaborators also described delays in diagnosing treatable physical health conditions, such as hearing loss and head injuries, which were described as associated with

dementia. At times, delays in diagnosis were described as due to healthcare professionals not listening to or addressing patient concerns. For instance, Marlene (First Nations, woman, 81) shared that a doctor initially advised her that she did not have hearing loss, despite her insisting on a change in her hearing. Knowledge collaborators also expressed concerns about the lack of quality diagnostic services in northern cities compared to those in southern and more populous areas. Delays in diagnosis and treatment were viewed to be more extensive for people living outside of the nearby city, due to even greater barriers to access care, such as a lack of transportation. For instance, Nolan described how First Nation people from rural communities may face additional barriers to accessing healthcare at the regional hospital:

> While I was in there, there was another family who were in from [northern town]. The nurse comes out and explains, unfortunately, we won't be able to get you in today so that you can book in at a hotel, and they were like “No, we can't, we have to go home”. So, all that way back to [northern town], and then coming back in the morning, you know, it's not an option [for them].

This illustrates how First Nation Peoples in rural communities in Northwestern Ontario face additional barriers to accessing healthcare services.

Knowledge collaborators also expressed concerns about racism in healthcare and how it may delay access to timely diagnosis and treatment. For example, Rob (First Nations, man, 61) shared instances where he believed First Nation individuals were triaged less urgently due to their racial and ethnic identity:

> You've heard stories so much about Native people going in, I've been there, actually, myself, and witnessed it. Sitting there [at the hospital]. They [the hospital staff] might not

> think that I'm Native, but the guy in front of me is, so he gets pushed back [of the diagnostic cue].

These broader and systemic influences on the risk for dementia emphasize the need for increased local, accessible, and culturally safe healthcare options in and for First Nation communities.

Knowledge collaborators expressed concerns over the role of pollution on the quality and health of the land, air, and water. Knowledge collaborators shared concerns over breathing in chemicals from a local paper mill, positioned next to a First Nation community, and how this might impact the risk of developing dementia. Knowledge collaborators also shared concerns over local non-FNMI communities polluting waterways (e.g., with sewage) used by First Nation communities for drinking water and the chemicals used to treat water. For instance, Birch (First Nations, man, unknown age), whose grandfather lived with dementia, shared their concerns over the quality of water and dementia risk:

> I lived in the [reserve] for awhile. Now I live in [city], and the water is completely different. It's totally different water. I don't notice the chemicals in the water in [river]. So those things take huge effects I believe. There are stories of not just mentally getting sick but your body. Your body over time takes effect of that. You go to a northern community, and a lot of people in the community have hip problems, knee problems, and that's all to do with the water. I feel that it's connected to [dementia] that way.

This illustrates how the quality and contaminants of water may increase the risk of developing dementia for First Nation people in Northwestern Ontario.

Knowledge collaborators also shared concerns over the impact of land, air, and water pollution on the accessibility and safety of consuming traditional foods. For instance, knowledge collaborators shared concerns over agricultural companies spraying pesticides on land used by

animals for grazing, and how that could impact the health of food consumed through hunting. They also shared concerns over the increase in mercury and chemical leaching in water systems by local natural resource companies, which others may consume through fishing. For instance, Pat (First Nations, Woman, 59) shared concerns over mercury poisoning in the local waterways in her community and how this influences fishing:

> I'm pretty sure [dementia] has lots to do with the food, everything that gets that's put into the food. Fish, you know the [northern lake] area, that fish over here, the mercury from the mill into the water system. The native people downstream eat the fish, that's mercury poisoning. That's a good example of stuff like that. The food chain has been disrupted.

A lack of access to traditional foods due to pollution was described as further complicated by the high cost of living, which provided another barrier to healthy diets. For instance, Aspen shared:

> Even in [reserve], there was this notice a couple of years ago, or even last summer, that there was too much mercury in the fish. With the food costs right now, it's cheaper to eat out at McDonald's than it is to buy a salad at the store.

Collectively, this highlights the broad influences of dementia risk among FNMI people in Northwestern Ontario, whereby the ability to make lifestyle changes, such as eating healthier, is heavily influenced by broader societal influences, including income and exposure to environmental contaminants. This emphasizes the need for broader and system-level changes and efforts, such as policy change, to influence the risk of dementia among First Nation communities.

Changes in First Nation ways of being, such as the disruption of the transmission of cultural values and teachings across generations due to colonization, and the introduction of technology, Western foods, and alcohol, were described as increasing the risk of developing dementia. Most knowledge collaborators highlighted that a change in dietary behaviours may be

a cause for the increased number of people living with dementia in their communities. Knowledge collaborators emphasized an increase in the consumption of canned, boxed, and processed foods, as well as foods containing steroids, hormones, and preservatives, and a decrease in traditional food consumption, which they associated with a rise in the number of people living with dementia. For instance, Balsam (First Nations, man, 54) and Fir (First Nations, woman, 50), who both had loved ones who lived with dementia, shared:

> Balsam: I think those kinds of diseases are becoming more modern. More modern-day. When I say modern, I mean my aunts and uncles. Their generation, when they started getting into a lot of these nontraditional foods. You know, a lot of sugar, salt, a lot of flour. A lot of dyed, all that dyed foods, right? And glucose…
>
> Fir: Preservatives
>
> Balsam: That's right. All that stuff, I think a lot of that stuff has to do with our diseases that we're going through now today.

This illustrates how the change in dietary habits, due to the introduction of Western foods, may be associated with an increase in the number of First Nations people living with dementia.

Changes in First Nations' ways of being were also seen as disrupting connected families and intergenerational relationships with Elders, increasing social isolation. For instance, Daryl shared how he has noticed a change in the younger generation’s connection with Elders:

> I had to choose between [going to work] and burying an Elder. This Elder gave my son his Indian name. Whenever we asked on him, he was always there. So, I told my son, "You're not going to school today, you're coming with me." We had a ceremony for this Elder. [I thought], where's the kids? Where are the teenagers? All you have sitting here around the casket was his brothers and sisters and a few other community members. This

> [Elder] was always at the graveyard, burying his people all his life. At the end, I don't know if people went there to go ask some questions about things. Like what it was like a long time ago. Maybe it could be because of all the selfishness that's going on in the world today. A lot of our Elders have slipped through the cracks, even when they have knowledge to give to you.

This suggests that disruptions in intergenerational relationships, possibly resulting from shifts in cultural values, responsibilities, and priorities due to colonization, may increase the risk of developing dementia in First Nation communities.

**Reducing the Risk of Dementia by Aging Well**

Knowledge collaborators shared and described a range of approaches to aging well, including walking, accessing healthcare services, hunting and fishing, raising children, writing music, and helping others in the community. While these practices were often mentioned in response to questions about aging well, related insights also emerged throughout broader conversations about dementia and community wellness. In many cases, these practices directly addressed the factors that participants associated with increased dementia risk, such as stress, social isolation, limited access to healthcare, and disconnection from land and community. Although the link between aging well and dementia was not always made explicit, these findings suggest that participants' understandings of aging well were closely intertwined with efforts to maintain brain health and reduce the risk of dementia through wholistic, culturally grounded practices.

***Caring for Our Whole Selves***

Aligned with a wholistic perspective of wellness, knowledge collaborators shared how caring for mental, emotional, physical, and spiritual wellness helped them to age well, effectively reducing their risk of dementia.

Knowledge collaborators shared how mental wellness facilitates aging well and brain health. Several knowledge collaborators described the importance of self-acceptance, self-esteem, perseverance, optimism, and autonomy in facilitating brain health and healthy aging. Moreover, several knowledge collaborators directly and indirectly emphasized the importance of cognitive stimulation. Knowledge collaborators shared stories, and images, of how they "keep the mind busy", or pursue cognitive stimulation, including through attending community bingo events, completing crosswords and puzzles ("sudoku", "word puzzles", "jigsaw puzzles", and "cryptogram"), writing music or journaling, wood burning, soapstone carving, crafts, reading, painting, drawing, playing music, learning new languages, learning from the land, learning through sport, beading, crocheting, and knitting. Many of these activities were taught to knowledge collaborators by Elders, elders in the community, grandparents, and parents. Nolan shared how he encourages his father to also engage in cognitive stimulating activities to keep his mind healthy:

> Every morning, I wake up and write for 30 minutes, and then I'll do a Boggle. And I think jigsaw puzzles and Lego are strong things. So those are the kinds of things, even though my dad doesn't ask for them, that's what he gets for Christmas now. I think if you don't use it, you're going to lose it; that's part of it. And so, keeping those circuits firing is good.

This illustrates the importance of cognitive stimulation in maintaining brain health and strong and connected families in facilitating healthy aging.

Knowledge collaborators also described a lifelong commitment and interest in learning new skills and activities. Donna (First Nations, woman, 64) shared an intrinsic motivation to learn through community events:

> Anything that's there, that's interesting, that I could learn something new, I go to. I never stop learning. Even if I'm not in that age bracket, I still go. You don't have to be old, lying in bed or doing nothing. I try to go all over if I can.

This motivation and interest in learning new things facilitated cognitive stimulation and fostered social connection, effectively reducing social isolation.

Knowledge collaborators also shared approaches to aging well by caring for their emotional wellness through healing from trauma, including adverse childhood experiences (e.g., sexual and physical abuse, attending residential schools), intergenerational trauma (e.g., residential schools), and trauma during adulthood. Several knowledge collaborators shared how reconnecting to their cultural identity helped facilitate this healing while fostering self-esteem, purpose, meaning, and intergenerational healing, which helped them to age well. For instance, Helen (Métis, woman, 46), who shared that she was not raised in her culture or community, shared her experience of healing from chronic interpersonal lifelong trauma through connection to culture at a local First Nations-led culture-based substance use facility:

> All those traumas dimmed [my] light. Like when you're born, you get, you know, when you see babies' eyes, they're jumping in the morning, and they're so beautiful […]. Mine was gone. It was, there was like a spark. That was it. But now, it's a little flame […] Hearing that drum, and that sage, it made it come back, and that's beautiful. So maybe that was what I was missing, and what I was not acknowledging, and that was a big thing I was missing. And now that I'm getting it back, my spark is coming back. And I love me now. I finally love me, and I respect me.

This illustrates the importance of local First Nations-led culture-based healthcare services, connection to culture, and reclaiming cultural identity towards healing from trauma and developing self-esteem, which were dementia risk factors identified by knowledge collaborators.

Knowledge collaborators also shared efforts towards supporting physical wellness to age well, thus reducing their risk of dementia. Land-based diets were described by several knowledge collaborators, including consuming salmon, moose, blueberries, rabbit, and beaver, as promoting brain health during aging. In addition, a few knowledge collaborators shared the importance of traditional medicines in facilitating brain and physical health. For instance, Joanne shared how she believes that consuming traditional medicines and diets across the lifespan facilitates brain health:

> My aunt used to tell me stories about her mom. She didn't have dementia. She wasn't sick at all. All they did was eat wild food when she was growing up. That's what made her live longer. And she drank cedar water. She said they used to go hunting, and she still remembers. She's 89 years old, and she still has a good memory.

This illustrates the importance of connection to land, culture, and physical health across the lifespan in facilitating brain health in older age. Other knowledge collaborators shared that connection to land also facilitated increased physical activity, such as walking and hiking. In addition, walking was described as helping to reduce stress and regulate emotions. Some knowledge collaborators also described approaches to physical wellness through sports, including ice hockey, golfing, and ice skating, which also facilitated social connection.

Knowledge collaborators shared how caring for their spiritual wellness facilitated a sense of meaning and purpose, emotional wellness, and connection to others. Spiritual wellness was achieved through connection to Creator and Christian or Catholic Faith, reading the Bible,

attending and participating in powwows, spending time on the land, and practicing ceremonies (e.g., sweat lodges). For instance, Paul (First Nations, man, 77), who provides care for his loved one living with dementia, shared the importance of the Bible and his faith towards aging well:

> I got in trouble with the law, and I was thrown in jail, and I was very depressed. I was 35 years old. I had enough of jail. I looked at it and I said, "The only way I'm going to see the other side is to end my life" (…). I started reading the Bible. (…). I was not saved at the time. I didn't know nothing about the relationship with the Creator and who was the Creator until I read the book about Jesus (…) And to this day I've been reading this book, for the past 13 years. I read it from cover to cover every year. (…) So, this is my health and my wellness and my being, where I know what this Word says.

This illustrates how a connection to faith can support emotional wellness and cognitive stimulation through reading. Other knowledge collaborators shared how a connection to Creator helps to support emotional wellness. For instance, Marlene, who brought her eagle feather to describe how it helps her age well, shared:

> When I'm really troubled, I just take one [eagle feather] and I go and sit, and I talk to my feather and tell them [the eagle feathers] what's bothering me. They take it to Creator. So, I've got ways to help me get through difficulties.

These sentiments illustrate the diversity of approaches to pursuing spiritual wellness in First Nation communities to reduce the risk of dementia and the interconnectedness of spiritual, emotional, and mental wellness.

### *Local and Virtual Wraparound Care Services*

Knowledge collaborators described the importance of local wraparound healthcare services in facilitating aging well. Several of these services were also associated with community-identified risk factors for dementia. Knowledge collaborators described accessing local in-person

and virtual mental health services (e.g., 24-hour help lines and telehealth) to support emotional wellness, including counselling, group therapy, psychiatry, and sponsors for sobriety. Joanne shared how accessing local mental health services through a First Nations-led health organization in her community helps to support her emotional wellness:

> [My counsellor and I] meet here on Thursdays. We make something or we eat something. [We talk about] what's bothering you. You bring it out. And you've got to trust that person for you to bring it out. And I trust [name of counsellor], 100 percent.

This illustrates the importance of local First Nations-led community-based mental health programs and the need for continuity of care providers in reducing the risk of dementia in First Nations communities. Knowledge collaborators also shared how accessing substance use programs, including local culture-based programs and Alcoholics Anonymous, helped them reduce substance use.

Knowledge collaborators also described accessing local healthcare to address physical health conditions, including injuries and hearing loss. For instance, Gzhie Manidoo (First Nations, man, 76) shared how obtaining a knee replacement at a local hospital helped him to continue walking, hiking, and hunting:

> For three years, I couldn't walk a hundred yards. It was bone on bone. So, somebody got sick, an old guy, and a doctor called, "You want to get your legs done?" After I got the two knees done, oh man, I can do everything. I can walk to the road and get my newspaper (…). I was hunting moose, and I did a lot of hiking.

This illustrates how access to local healthcare services can facilitate physical wellness, including physical activity and access to traditional diets. In more rural communities, knowledge collaborators described the importance of regular access to travelling healthcare providers, such

as nurse practitioners, in helping them to manage physical health conditions, such as type 2 diabetes.

Knowledge collaborators also shared the importance of culturally safe mental and physical health services. For instance, knowledge collaborators shared positive experiences of accessing Elders for guidance for emotional wellness, accessing sweat lodges, and Indigenous mental health counsellors. Knowledge collaborators also shared the importance of access to traditional medicines for emotional and physical wellness, highlighting this as an area of need.

Knowledge collaborators also shared the importance of community-based programs and opportunities for First Nation elders, including psychoeducation programs, formalized peer support networks, leadership roles on First Nation councils, social programs (e.g., bingo), cultural health programs led by First Nation health organizations, and programs to connect elders with youth and the land, in facilitating aging well. These programs supported social connection, health psychoeducation, and transmitting cultural values across generations. For instance, Moon (First Nations, woman, 46) shared how a monthly gathering for elders held by a local First Nations-led health organization in her community helps to reduce social isolation:

> That was the first time I went out in three weeks is when I did that [gathering held by local First Nations-led health organization] thing. I barely leave my house, so it's hard for me to make any connections.

This illustrates the importance of regular gatherings and programs for elders to support social connection and reduce social isolation. However, cultural programs specific to elders were highlighted as needed in rural and urban communities. For instance, Tracy shared a lack of programs for elders in her rural community:

> I even said that at the moose camp [for youth], I go where are our elders? How come you guys didn't bring them out? You guys could have at least brought them out for one hour from the hospital and took them back. They would have been happy. They would never, never felt forgotten about because I think that's what exactly is happening in this reserve is they're forgetting about the elders.

This illustrates the importance of ongoing initiatives to support aging well for elders living in rural and urban communities. Additional community-based wraparound care that helped support aging, including addressing community-identified dementia risk factors, included community-based health fairs, home cleaning, community and home gardens, and transportation services.

### *Aging Well is Relational: Strong Kinship Networks, Strong Aging Mind*

Through stories shared and observations during the knowledge-gathering circles and group interviews conducted with family members, it was evident that strong and connected families were critical to aging well among First Nations Peoples in Northwestern Ontario. The importance of strong families is embedded in a context of historical loss and disruption of families due to Residential Schools. Marlene described how colonization negatively influenced families, impacting the wellness of elders:

> Most of our people my age were in Residential Schools, and they ended up not speaking the language or knowing anything about the culture. Families were broken up, and all the government rules and regulations that we had to live under were demoralizing. This really caused a lot of hardship for families. And they really broke up our families.

Connected families, facilitated through visiting, living in multigenerational homes, spending time on the land (e.g., camping, hiking, fishing, and hunting), storytelling, and sharing meals, helped facilitate mutual social and emotional support, love, joy, care, concern, connection and

belonging, physical activity, and health monitoring. For instance, Pine shared how her connection to her sisters supports her emotional wellness:

> I have two sisters, and I adore them. I am so grateful for what they do for me. There are times where I can't get up off the floor, mentally, not physically, but you know, just contact with them. I'm right back at it again, and I'm grateful for that. I need them.

Connected and caring families also help to facilitate mental and emotional wellness by supporting sobriety and harm reduction. Maple (First Nations, woman, 65) shared:

> In my family, we have a lot of us that are sober. There's me and my brother and my other two sisters. So that's four of us that live a sober and clean life today. We work together as a family and for any problems we may have; I could go to any of them, and they will help me.

This illustrates the importance of connected and healthy families towards reducing the risk of dementia through emotional wellness, including reducing alcohol use and promoting sobriety.

Connected families also helped to support elders who experience mobility limitations and ensured access to healthcare services. For instance, Maggie shared how her family supports her by providing transportation for medical appointments:

> [My family] won't let me drive anymore because I was sick when I had cancer (…). My granddaughter drives me. Sometimes she takes me to the doctor. [My family] helps me. Sometimes when I get tired, and they think that I'm tired too, they cook. They do a lot.

This suggests that connected and healthy families are instrumental to aging well for elders through facilitating social support, transportation, access to healthcare, and meal preparation.

Partnerships, such as spouses, also supported aging well and addressed identified risk factors. Partnerships were evidenced to support emotional support, joy, health monitoring,

physical activity, memory recollection, sobriety, and mutual love, care, and concern. For instance, Willow, who shared photography memory discs as an object of what helps her age well, shared how reminiscing on experiences over her long-term marriage of 60 years helps to foster memory recollection and wellness:

> Now we can't travel because of health issues, but we reflect on that, all those things that we did, and we see [places] on TV, and we'll say, "Hey, we were there." So, it has helped us in coping today with what our limitations are, just knowing we had the privilege to participate in that. We did that for ourselves (…). We've had some awesome trips that give us good memories, it just keeps us happy and involved and reliving things.

This illustrates how long-term partnerships support emotional wellness through mutual coping and self-acceptance of age-related limitations. In addition, long-term partnerships facilitated emotional wellness by processing difficult childhood experiences. For instance, Irvine (First Nations, man, 84) shared:

> I talk to [my wife] about things that happened to me all my life. It helped me, she understands what I am talking about. She’s been with me for 65 years. It was hard for me to come out and talk [before] then. Because when I was in the bush, I was all alone. Sometimes three weeks at a time. Never talked to nobody. Just talked to my dogs.

This illustrates how long-term partnerships can facilitate emotional wellness and coping while reducing social isolation across the lifespan for First Nations people.

Connection to community was also described as facilitating aging well and addressing several identified risk factors for dementia. Knowledge collaborators described how engaging in and watching sports with friends, including ice hockey, ice skating, and golf, helped to facilitate social connection and physical activity. Peer support networks were also discussed as facilitating

social connection, learning, belonging, and accepting age-related limitations. Marlene shared how informal support networks with other elders help to facilitate social connection and emotional wellness:

> A lot of us don’t have that opportunity to talk with each other and share what's going on in our lives around these issues, like elder abuse (…). When I'm in Walmart, I'm there for an hour because I not only shop, but I've got to talk to everybody, and they share everything with you. So, I'm hearing a lot of these stories. Women my age talk about elder abuse, especially around their money. The kids keep wanting their money and stuff like that. They're shy to share that or do anything about it. But they will talk to me, but I don't know if they talk to anybody else.

Marlene further emphasized the importance of community organizations and First Nation band leadership support to develop formal networks for First Nation elders to connect and access support related to aging, including addressing elder abuse and changes to cognition, hearing, and vision.

In addition to connection with family and community, connection to non-human kin, such as animals (e.g., pets) and the land, also facilitated emotional wellness. Knowledge collaborators shared how time spent with the land and water reduced stress, and increased a sense of purpose, social connection, brain health, and learning First Nations ways of being and doing. April (First Nations, woman, 63) described how her connection to ancestral rivers fosters a sense of purpose and meaning:

> I brought water walk ceremonies to [city] (…), which came from my first water walk in [year] when I joined the late grandmother Water walker on her last walk. When I returned home from that walk is when the river spirits here started to tell me that I need to do

> something. To help bring healing to the rivers, not only because of the deaths that were happening with our Indigenous youth being found in these rivers over a period of years, but also the pollution and everything that is affecting our waters.

This sentiment illustrates how connection to non-human kin, such as rivers and lakes, helps to facilitate a sense of purpose and meaning, social connection, and physical activity, while also helping to bring awareness to larger systemic challenges identified by knowledge collaborators as increasing the risk of dementia, including water pollution.

### *Cultural Continuity Through Intergenerational Relationships Supports Aging Well Across the Lifespan*

Cultural continuity refers to the transmission of culture across generations, including how this transmission occurs. Cultural continuity and connection to culture have been associated with improved mental health and wellness, such as reduced youth suicide, among First Nation communities in Canada (Chandler & Lalonde, 1998). Similarly, cultural continuity, expressed through intergenerational relationships between youth and elders, was discussed by knowledge collaborators as promoting brain health and healthy aging. These relationships supported wellness for youth, some of whom are now elders themselves, and for elders past and present. In this way, aging well through intergenerational relationships was understood to be reciprocal and regenerative.

Elders involved in the study described teaching youth about mental health and wellness, including the importance of reducing alcohol use, and supporting cultural identity development through transmitting cultural values, ceremonies, music, and language. Several knowledge collaborators shared that intergenerational relationships with elders in their community supported youth in setting goals, such as pursuing education. April described that teaching language, cultural teachings, and drumming brings her a sense of purpose and youthfulness:

> Now that I am retired, I'm doing a job I love that feeds my spirit. When I'm going into the schools to spend time with children, that is the highlight of my day. I look forward to that and I can't wait to get to bed and wake up in the morning to get there so I can see their smiling faces and sing with them (…). It helps me age well, too, because it makes me feel young when I'm with the young at heart.

This reflection illustrates how intergenerational relationships between elders and youth help facilitate identity development and foster a sense of purpose by revitalizing traditional roles for elders in the community.

Knowledge collaborators also reflected on their experiences as youth, recalling how they learned about cultural values and ways of being through relationships with elders. Connections with elders and Elders, including parents, uncles, aunties, and other community members, helped foster a sense of purpose (e.g., through naming ceremonies). In addition, knowledge collaborators described how intergenerational relationships taught them about loving and healthy relationships, cultural values, land-based activities, traditional medicine, ceremonies, caring for mental and physical health, and skills such as beading and knitting. For instance, Daryl shared how growing up connected to Elders helped him establish a strong sense of identity:

> What the Elders would always say, "You know, this is how it is for us. This is our family. This is what we believe in. This is what gives us life." So, they talk about, Anishinaabe ceremonies like a sweat lodge and shaking tents and powwows. They teach things like fishing, hunting, and blueberry picking (…) I don't know if they've made me well. I like to think so. [These experiences] add up to the person that I became today.

Several knowledge collaborators described these practices and activities as instrumental to aging well and associated with brain health. In some cases, elders also served as role models for youth

and modelled cultural values through their actions. These cultural values helped to pass on a tradition of community care and helping others to youth and emphasize the importance of connected communities. For instance, Jocelyn (First Nations, woman, 87) shared:

> The one they were talking about; they'd go on a boat right at the point here. And they'd go see their net. And they'd bring fish and everything. And right beside my home, there, and her home, they'd make a fire. They'd start cleaning their fish. They'd make a big pot of fish, Christian potatoes and Bannock and everything. And then she comes knocking at my window. She says "*bidaa wiisin! bidaa wiisin*!" That means "Come on and eat." That's how they were. Always.

These sentiments emphasize the importance of frequent opportunities for elders and youth to connect, and illustrate the lifelong reciprocal influence these relationships have on aging well across the lifespan among First Nation Peoples in Northwestern Ontario.

### *Using Our Gifts in the Community*

Beyond intergenerational relationships, knowledge collaborators also described how helping others facilitated aging well for themselves and others. Knowledge collaborators described various roles in the community, such as teaching others, preparing meals for others, praying for others, sharing food, leading programs (e.g., beading workshops), developing community-based programs (e.g., land-based programs for youth), supporting peers, and providing leadership on committees. For instance, Joanne (First Nations, woman, 58) shared how she and her family share moose with the elders in her community:

> If we get a moose, a big moose, we share it with the people on the reserve. The elders. And give them a piece, [so they] can make some stew.

This sentiment illustrates an approach to helping others within the community. Knowledge collaborators described how helping others in the community helped to facilitate a sense of

purpose, spiritual wellness, social connection, and a community of care. For instance, Nolan, who contributes to his community using his passion for writing music, described how helping others in the community facilitates a sense of purpose and a community of care:

> Once a week I go and hang out with MC [name], my special needs guy, and we do our word warmups first; we always start with a wordle, and a daily jumble, and the Boggle. When he lights up, I light up. I've also been helping out in the kitchen, at the [shelter] (…), I leave there and I'm like, you know what, like, it's not a comparison thing either, like I feel a lot better because I am not there, you know? It has nothing to do with that, it's just that [helping] is soul food.

This sentiment illustrates how finding and using one's gifts in service to the community facilitates a sense of purpose and wellness for the helper and the person receiving the help.

A desire to help others and contribute to the community was facilitated by several underlying values, often transmitted through intergenerational relationships, including love, humility, reciprocity, and respect. For instance, Daryl shared how values of helping have been passed onto him through sobriety programs and First Nation values:

> People call the whites, the light-skinned race, wašíču. So, then the definition of what wašíču means is to become rich. Collect things of value and base their life on those types of things. So, whereas the opposite way could mean to give, rather than to take. [Alcoholics Anonymous] tells you that in order for you to live free from your disease, say alcoholism is a disease, (…) and to be a complete person, you have to give things away. And by giving it away, you get life back from it, for you to live. Same thing, Anishinaabe, even when you're going to your ceremonies and giving your tobacco, it returns to you and

> gives you life. You eat your duck and your geese, you shoot it and kill it and eat it in soup, it gives you its life. It's a give and take.

This sentiment illustrates how cultural values, often transmitted across generations through intergenerational relationships, can underscore an ethic of helping others through a belief in reciprocity.

**Wholistic Assessment of Dementia**

Knowledge collaborators shared a similar trajectory of accessing assessment and diagnostic support from healthcare providers for their loved ones living with dementia, beginning with family members noticing changes in their relative. These changes included shifts in socialization, emotions, behaviours, and cognition. Moreover, knowledge collaborators shared how the severity of symptoms also appeared to vary based on the relative's medical history, current environment, and access to culturally safe care.

***Families and Healthcare Providers Support Loved Ones on Their Assessment Journey***

Knowledge collaborators shared that, as family members with regular and close contact with their loved ones, they were often the first to notice changes in their socialization, emotions, cognition, and behaviour. Knowledge collaborators were less likely to share that a healthcare provider was the first to notice symptoms. For instance, Ed (First Nations, man, 75) shared how he noticed changes in his grandfather, which his grandmother initially observed:

> We loved Coca-Cola and ice cream, so we would always go to his house. As kids, he would always have it there for us. Then we started noticing his fridge was full of Coca-Cola and ice cream. So, Grandma would tell us something's wrong with him. He keeps going to the store, buying Coca-Cola and ice cream. Now I think about it, there was something wrong with him. Years later, we found out it was Alzheimer's.

This illustrates the importance of psychoeducation in identifying the signs and symptoms of dementia within First Nation communities. For instance, in some cases, a lack of awareness of dementia symptoms delayed care seeking.

The stories illustrated that knowledge about dementia, including signs and symptoms, helped expedite seeking assessment services and diagnosis. Having previous experience of dementia within the family, such as having a grandparent with dementia, facilitated identifying early symptoms and accessing assessment services. In other cases, knowledge collaborators shared that they initially discussed changes with friends and family before seeking a formal assessment. Two knowledge collaborators shared how, in some cases, loved ones may have denied or concealed symptoms, potentially due to a risk of leaving their homes to access long-term care, which delayed assessment and diagnosis. Unanimously, knowledge collaborators sought Western-trained medical professionals to conduct the assessment or obtain a referral, such as a family doctor, gerontologist, or psychologist. For instance, Paul noticed changes in his loved one's cognition, which prompted him to seek out an assessment and diagnosis through a healthcare provider:

> I got him checked out, and we went to see a doctor. That is when they were saying, yeah, there he's got something wrong with him, dementia.

This illustrates the important role of family members in the assessment journey, as well as access to local healthcare services with professionals who are trained on identifying symptoms of dementia. In one case, a knowledge collaborator who is presently undergoing assessment for dementia shared that access to an Elder during cognitive assessment would improve care. Due to a lack of people living with dementia involved in the study, this perspective was not explored with others.

***Dementia Influences the Whole Self***

Knowledge collaborators shared that they noticed changes in the loved one's social behaviours, such as isolating others and refusing to attend social events. Changes in cognition were predominately discussed, including personality changes, perseveration and paranoia (e.g., believing a spouse is being unfaithful), not recognizing family members, changes in judgement (e.g., increased spending), lack of awareness of current impediments (e.g., refusing help), hallucinations and delusions, and confusion. For instance, Odette (non-FNMI, woman, 62), whose parents live with dementia, shared how a lack of awareness of current difficulties can impair help-seeking:

> We really want to get my father into a home (…). He's getting harder for my mom to take care of because she's 90. My mother does not want him to go into a home, so I know I'm going to have to be the bearer of bad news and say, "It's time." I can put him in a home, and because he hasn't been declared incompetent, he can say, "No, I'm not going," even though he doesn't remember things.

This illustrates the difficulty that caregivers can experience while managing the safety of their loved ones and changes to their self-awareness of the extent of their difficulties.

Knowledge collaborators also described that loved ones experienced a wide range of incidents of forgetting, including repeating stories over multiple days and weeks, rapid memory loss (e.g., repeating themselves within a short conversation), forgetting to eat and take medications, making repeated purchases, forgetting recent injuries or conversations, forgetting how things work (e.g., forgetting what windshield wipers are) and how to carry out tasks (e.g., forgetting how to eat or drink), and forgetting loved ones. For instance, Maple shared how her grandma, who lived with dementia, was not able to recognize or remember her son:

> When my dad passed away, my granny was in long-term care. We brought her home for that. We looked after her. We all took turns. But every time we took her up to where my dad was, she would ask us who that was, and we tell her my dad. Then she'd start crying. So, all the way through the days he was here, and right up to the end, she always forgot who he was.

Experiencing a loved one living with dementia forgetting a family member was described as mutually distressing. However, despite changes to memory, knowledge collaborators often described that their loved ones had preserved long-term memory. For instance, Jane shared:

> She turned to me and said, "They didn't give me my Tylenol." I said, "You got something much stronger than Tylenol." But she had no recollection of just having had the medication. But she could sing a song from the '50s in English perfectly.

This illustrates how loved ones often experience difficulties with short-term memory but can recall longer-term memories more easily.

Knowledge collaborators also shared instances of their loved ones “going back in time”, acting out or reliving memories, or “returning to childhood”, such as writing diary entries from 10 years ago, preparing to go fishing or to work despite being hospitalized and retired, and asking for deceased family members. For instance, Moon shared experiences that her friend had while caring for her father with dementia:

> He'll constantly ask for his wife, even though his wife passed away. He would be like he was a kid again. Like “I'm going to go out and play”.

In some instances, “going back in time” led to changes in the language spoken with others. For instance, Nicole shared how she notices that some residents living with dementia revert to speaking Anishinaabemowin:

> Sometimes, a lot of language, they're less talkative in ways, but I kind of like chalk it up to it because often they're my language speakers, and so I'm kind of noticing that. Maybe it's them kind of going back to whatever stage of life, they were in where they're more comfortable. And so, they kind of lose the English and go back [to Anishinaabemowin].

This illustrates the need for access to language speakers or translators when caring for knowledge collaborators, to help reduce distress and social isolation among First Nation Peoples living with dementia in Northwestern Ontario.

Knowledge collaborators also shared how the behavior of their loved ones changed as they aged with dementia, including changes in self care (e.g., refusing to eat, not being able to cook for themselves, not doing their make-up, not bathing), requiring additional assistance with daily living activities, reduced confidence in independent living, and increased falls. For instance, Tracey (First Nations, woman, 59) shared how a community member living with dementia, who initially lived alone prior to being moved to access long-term care in a town several hours away, refused to eat:

> ISN [Indigenous Services Canada] (…) took him [a person living with dementia] food because he wasn't even able to cook for himself last year. He just wouldn't eat. You'd even take him food, and you'd find all that food piled in the fridge. He wasn't eating it.

These changes in behaviour and self-care underscore the need for available and consistent in-home care in First Nation communities, and education programs for family members and paid care partners supporting loved ones living with dementia and changes in behaviour.

Knowledge collaborators also shared stories of their loved ones living with dementia, wandering, and getting lost. For instance, Maggie shared a story of her mother-in-law, who lived with dementia:

> One time when she was in the hospital, somebody found her walking around in a blizzard in the winter. She had only a blanket, and she used mittens for slippers, those blue ones. She would have froze. I guess the nurses didn't see her once she went outside. There was another Indian lady who recognized her. She was the one who found her walking. She said, "Where are you going? It's nighttime." She told her, "I don't know where I'm going, I don't know where I am."

These changes in behaviour, such as wandering and getting lost, underscore the need for comprehensive care, training, and supervision when supporting First Nations Peoples living with dementia in Northwestern Ontario.

Knowledge collaborators also shared several changes in emotions observed in their loved ones living with dementia. Knowledge collaborators shared how loved ones living with dementia became more easily agitated, aggressive and violent (e.g., throwing items at family members), angry, “mean”, fearful, and lost interest in activities. At times, these emotional changes would negatively impair relationships with loved ones and create barriers to accessing care. For instance, Robert (First Nations, man, 62) shared how he noticed changes in how his grandfather engaged in relationships with others in his family towards the end of his journey with dementia:

> Robert: He really did not like his wife by the end of it. Just could not stand being around her, which is a horrible thing to say. His attitude towards people. He was very friendly, but if he didn't like you, he didn't like you. That was that way. He had very low patience for people. If you weren't doing it right, you were an idiot. Don't bother me.
>
> Brittany: And that was a change from before?
>
> Robert: Yeah, well, partly. He was there, but he never really put it out there. There was no filter at the end of it.

This illustrates how emotion regulation changes may also impair relationships, leading to care partner distress. Changes in cognition were also described as interconnected with changes in emotion. For instance, lapses in awareness due to changes in cognition were described as connected to increased aggression towards care partners. Birch shared how a shift in cognitive awareness led to confusion and aggression in his grandfather:

> I know when my grandfather was found out by the dock, it was almost like he was reliving a memory. He told us that he was getting ready to go for a [boat] ride. He had a boat ride or something with some individuals. It was almost like he was like a daydream kind of attitude, and he was reliving that memory. That's how he was out there. But I noticed when they wake up from that, it's almost like confusion, and that's where that aggression and anger come from, right?

This illustrates how changes in cognition can perpetuate increased changes in emotion regulation and expression among loved ones living with dementia.

Changes to the spirit were mentioned less frequently by knowledge collaborators. Interestingly, some knowledge collaborators shared that they felt the spirit does not change when someone is living with dementia. For instance, Maple shared:

> My understanding of the spirit is that with dementia, your spirit doesn't change. In us, all of us, like myself, I have my spirit, and my granny had her spirit. So, that never changed because our spirits are the ones closest to the Creator. When we're going to go, our spirits are whole. It doesn't matter if we had dementia. It doesn't matter for Alzheimer's. That spirit that lives in each one of us, like my granny, that spirit was whole, and she was still the same person without the dementia. The spirit goes to the Creator.

While a few knowledge collaborators echoed this, others were unsure how to determine whether a person's spirit changes and encouraged that this be asked of people living with dementia.

Aligned with a relational identity perspective, knowledge collaborators described how relationships and social factors impacted the course and severity of symptoms. Through the stories shared, it was apparent that each loved one's journey through the course of symptoms was unique. Knowledge collaborators shared how symptoms "come and go" and where the severity and presence of symptoms may vary. For instance, Willow shared how symptoms of dementia can vary in their presence and severity:

> Dementia can change; you can have good days; you can have bad days. I've seen people recognize me one day but not recognize me the next day.

Change in the severity of symptoms underscores the need for frequent and regular contact with elders, to help identify early changes in their wholistic presentation.

A few knowledge collaborators shared how the severity of symptoms also seemed to depend on the loved one's history, the current external environments, and access to culturally safe care. For instance, Nicole shared that she has observed a faster decline among Residential School survivors in long-term care. She further shared how access to culturally safe care, such as access to cultural supports and ways of being in relationship, may influence the severity of symptoms among people in long-term care:

> Nicole: For me, it doesn't feel like it's someone that's living with dementia, whereas I'll go and read their chart, or I'll hear, oh, this happens. I've never seen that side of that person.
>
> Brittany: Why do you think that is? Like the difference in the severity of symptoms.

> Nicole: I don't know if it's just because the spaces we create for them are just comfortable. It kind of takes them back to whenever they were last in that space. It seems like they're like living present. Versus like when they're back in, whether it's the institution or with maybe it's a certain nurse or care person that maybe they don't have that relationship with.

This suggests that the environment and quality of relationships, including culturally safe care, can influence the severity of a loved one's dementia symptoms. Collectively, however, knowledge collaborators shared that symptoms were, in most cases, progressive and became worse over time, regardless of the setting. Moments of lucidity or awareness became less frequent and then ceased altogether, which increased the extent and type of care needed.

## Caring for Loved Ones Living with Dementia

Knowledge collaborators shared a unanimous preference for their loved ones to age in place and noted that their loved ones also expressed a strong desire to remain at home as they aged with dementia. Participants described diverse experiences related to providing care to loved ones living with dementia, including navigating paid and unpaid caregiving, accessing and providing culturally safe supports, and encountering unmet needs for aging well with dementia. Although challenges to aging in place were common across the communities visited, participants living in more rural areas reported additional, unique barriers to care.

### *Wraparound Care Honours Loved One's Wishes to Age in Place*

Knowledge collaborators shared that families and their loved ones often prefer to age with dementia at home. Birch shared how his family worked towards supporting his loved one to age in place with dementia in their rural First Nation community:

> I remember my [with my] grandfather, my grandmother wanted to keep him home, and they would lock all the doors on him. So, to keep him inside. They kept him at that house for as long as they could.

This illustrates the preference to age at home and the importance of connected families in supporting aging in place. In some cases, however, aging at home was deemed necessary due to a lack of local alternatives.

Aging at home was described as primarily supported by multiple family members, including spouses, siblings, children, nieces and nephews, and grandchildren, who were willing to provide live-in support. However, in some cases, care was supported primarily by a sole family member, often a woman, such as a daughter or wife. Knowledge collaborators shared that family members assist with a wide variety of tasks, often 24 hours a day, including managing finances, grocery shopping and providing meals, supporting hygiene (e.g., toileting and showering), providing reminders, coordinating healthcare appointments, driving to appointments, monitoring symptoms, providing social connection, coordinating and monitoring paid in-home care providers, and ensuring safety (e.g., from wandering or leaving appliances on). For instance, Moon shared how her friend, who is the primary caregiver for her loved one living with dementia, provides care 24 hours a day, which extended family members often supplement:

> The biggest problem was when they would go to sleep, someone would have to stay up. They had to rotate 24 hours because her father would end up leaving the house. He'll walk around in the middle of the night. So, they had to take shifts like that. So that was hard for them in that sense. He would put food away in his closet. Like, just really a lot of [challenging] behaviour.

This illustrates the comprehensive care that is necessary when caring for a loved one living with dementia, and the importance of external family members who can provide respite.

In some cases, and early in the dementia journey, loved ones continued to live at home, with support from family members living nearby. This underscores the importance of close and connected families, who are proximal to the person living with dementia, in supporting loved ones. For instance, Anonymous shared how family members living close by and local health care services help to maintain independence among a loved one living with dementia:

> They have workers going in for home care for her, because [her husband] works out of town for two weeks at a time, and then he comes home for two weeks. She gets that care for personal support at home care, and her sister lives across the road, so they go and check up on her.

This illustrates the importance of proximal family members in supporting the independence of loved ones. However, knowledge collaborators shared that not all loved ones have family members willing to provide care. A lack of available and willing family members was viewed as a barrier and challenge to many loved ones who prefer to age at home. Other barriers included inter-family distress, a lack of housing with adequate space and accessibility features, and a lack of in-home paid care partner support (e.g., personal support workers). In some cases, these barriers led to the loved one being transferred to long-term care hours away from their home and community.

Knowledge collaborators, often not directly related to the person living with dementia, were also helpful in aging in place. Connected and caring communities, who were aware of a community member living with dementia, helped to provide social support and connection (e.g., visiting to reminisce on past experiences), preparing meals (e.g., “people in the community cook

for elders"), home maintenance (e.g., "snow clearing"), and to monitor behavior for safety (e.g., wandering). For instance, Aspen (First Nations, woman, unknown age) shared:

> I think we're really fortunate to have [First Nation community close to large city], even my reserve, that is closer to a city to access health care. I know of stories that are like more remote communities that it's more the community that checks up on people, like they'll see them wandering around the community. They'll contact the family and your relatives around the community to just be mindful. So, if you think of more remote communities, it's the family and the community that care for that individual.

This illustrates the importance of close, connected, and caring communities to support the family and person living with dementia and support the safety of the person living with dementia. Moreover, it illustrates the additional considerations when caring for loved ones living with dementia in more rural communities.

Aging at home was also described as supported by in-home paid caregivers. Several types of helpers were described by knowledge collaborators, including travelling doctors, social workers, personal support workers, and local care navigators (e.g., to attend medical appointments), nurses, home care workers, homemakers (i.e., paid caregivers who provide cleaning services and prepare meals), and transportation services. In cases where knowledge collaborators did not have access to a vehicle and/or lived remotely, low or no-cost transportation services were instrumental in providing access to healthcare services and grocery shopping.

Paid in-home support was described to assist with monitoring blood pressure, symptom monitoring, food deliveries, preparing meals, medication, hygiene, home cleaning and maintenance, and social connection. For instance, Anonymous shared how local paid in-home care providers help with symptom monitoring for loved ones aging in place with dementia:

> [The personal support workers] come out, at first, they'll come out maybe three times a week or even every day, and then they'll slack off as you get better or if they see that you need it, and maybe even go three times a week. And then they will -- they keep notes on them. So, if they see that they're getting worse, then they'll know, they tell their family that it's time for them to go into a nursing home or if they can get somebody in living with them to keep an eye on them, day and night.

In cases where in-home paid care providers were available, knowledge collaborators shared difficulties with access due to low staffing. Despite the importance of local in-home paid care providers, these services were described as limited in some more rural communities.

Knowledge collaborators shared that oftentimes, symptoms would become too severe to manage at home solely by family members. This experience was described to lead family members to decide to move their loved one to long-term care facilities. In other cases, a lack of local healthcare supports in rural First Nation communities (e.g., homemakers), family dynamics, waitlists for in-home care in rural First Nation communities, and poor living conditions in the home (e.g., lack of accessibility) led to transferring loved ones to nearby towns and cities, often several hours from their home. Moon shared how an increased burden of care led to a loved one being moved to long-term care:

> When she could no longer do it, or when it became too difficult, because, like, he would go on those breaks, where sometimes he would like to throw things around, like he became a little agitated. She couldn't handle him anymore. So, [the family] just agreed with her, because she was the sole caregiver, once she could no longer do it, then they all said, okay, well, it's time to put him in long-term care.

This illustrates how increased caregiver stress, often associated with a lack of local healthcare services, can lead to loved ones being moved to long-term care, despite preferences to age in place. In some cases, knowledge collaborators living in or near a large city noted that the proximity of long-term care facilities helped ease this transition.

Knowledge collaborators shared that, when transportation was available, visits from family and friends in long-term care helped to facilitate the wellness of loved ones living with dementia in long-term care. The importance of connected families and communities and connection to land for aging well further underscores the need for local services to facilitate social connection and wellness.

Several knowledge collaborators expressed concerns about the cost, distance, and limited accessibility of long-term care, including long wait lists. For instance, Aspen shared concerns over the impact of the affordability of long-term care, and how this may lead to elder abuse:

> If they do get sent home because they can't afford a long-term home, then that's where a lot of elder abuse comes, right? So even just the affordability for our loved ones for a home [is a barrier], a lot of people are just making it by.

This illustrates the need for more local, affordable, and accessible long-term care options for loved ones living with dementia, and the potential consequences of barriers to care.

A preference to age at home, a lack of local residential care facilities due to living in a rural community, and a lack of available family members to provide care may lead some loved ones to conceal their symptoms. For instance, Balsam shared:

> A lot of elders around here think, because they've already seen a lot of their friends like get sick, put them in the hospital, and then shipped off to [town] to go die. Right? So, a lot of elders here, they're like, "No, I'm not going to doctors. I'm not getting diagnosed

> with nothing. I'm staying home, dying here." So, they prefer to get cancer, prefer to come down with whatever and die here, than go [and leave the First Nation community]. That's why a lot of elders refuse to go doctors. And if they do get told by doctors that something's wrong with them, they don't tell anybody in the family.

This illustrates the need for local wraparound supports to facilitate early assessment and diagnosis, and aging in place for as long as possible.

Across the rural and sub-rural First Nation communities visited, there were no options for long-term care within First Nation communities, while some had access to residential care. Willow shared their perspective on the need for on-reserve long-term care or assisted living to support elders, including those living with dementia:

> We were looking forward to the fact that a few years ago before COVID-19 hit, [local healthcare organization] was going to build a long-term care and residential supportive housing here [in the First Nation community]. That fell through. I mean, to me, that is something that would really benefit our elders here now. And, for the elders, we know a few from different reserves up there. Their elders need long-term care. They go into town here; they're sent here into town. They're a little Indian sitting in the corner, and all the white people are out here.

This illustrates how, oftentimes, elders, including those living with dementia, must move from their home communities to access long-term care or assisted living.

Knowledge collaborators also shared concerns regarding long-term care, including social isolation, lack of staff, harmful staff behaviours (e.g., speaking negatively to and about residents), prejudice, and racism. For instance, Willow and Poplar shared an experience of a

family member exposed to potentially racist treatment by healthcare providers in a long-term care facility in a nearby city:

> Poplar: Well, there was one nurse, a couple of nurses that came in to, like, during the night. In the evenings, and she would treat [name] like crap.
>
> Willow: She knew it was culturally based. It was just not verbally said out loud, but just that response of, you know, (…) there's not that eye-to-eye contact, and you're [not] seeing me as a person. You're just seeing me as a native person.

Concerns over racism and prejudice within long-term care were confounded with a mistrust of non-Indigenous healthcare services, described as due to the history of colonization and trauma. This underscores the need for additional efforts towards culturally safe care and First Nations-led healthcare services.

***Culturally Safe Dementia Healthcare***

Regardless of the location or type of care from paid care partners, knowledge collaborators emphasized the need for culturally safe care, personalized to the person living with dementia. Culturally safe care included access to cultural activities, powwows, drumming, blueberry picking, sweat lodges, ceremonial fires, First Nation ways of being in caregiving relationships, and a distinctions-based approach that respects each person's unique identity. For instance, Jocelyn shared how she approached caring for a loved one in long-term care with love and respect:

> [The hospital staff] put me with this old lady. She couldn't see, couldn't hear. She fought them. She was so frustrated, angry. She had bedsores, and she wouldn't let them touch her. I just went like this to her [rubs her arm]. I just touched her gently, like that, letting her know it's okay. Calm her down. And that's what I did with that little old lady. She started letting me move her, clean her bedsores. I think it's just love and showing you care

> for these people that are - nobody understands them, why they're the way they are. But you just got to show them the gentle side of you inside.

Others attending the knowledge gathering circle with Jocelyn shared how their family members working in healthcare roles would use similar approaches with their clients. This illustrates how culturally safe approaches to care can help with the physical and emotional wellness of loved ones in long-term care. Nicole further shared how access to drumming and ceremony in long-term care homes can provide a sense of purpose, meaning, inclusion, belonging, connection to community, and memory recollection:

> I have another resident who we didn't know, but she was the founder of the local drum group. For our sacred fire that drum group, there are women's hand drum group. [The long term care facility] were doing different events and ceremonies throughout the four days, and they were one of the invited groups. This resident loves drumming, so we made sure to bring her down. The group was like, “Oh my gosh, like, it's her, like, we haven't been able to find her in years,” and they invited her up to sing and gave her one of their drums and she sang (…) We really didn’t know, because again, this is another resident who doesn't have any family here so how would I ever know? She eventually she did remember. But if I asked her now about it she wouldn't. But if they were to come again, she would.

Nicole shared several cultural events in the long-term facility that appeared to facilitate memory recollection of residents and improve symptom severity. However, it was further noted that each resident in care may have a different experience of culture. Thus, a distinctions-based approach that respects each person's unique identity and preferences was necessary.

### *Caring for Care Partners*

Although not always stated explicitly, many knowledge collaborators who provided care to loved ones living with dementia appeared to be guided by cultural values such as respect for Elders, reciprocity, and love, which seemed to underpin their caregiving efforts. For instance, Diane (First Nations, woman, 37) shared how a respect for elders underscores her approach to caring for loved ones living with dementia:

> Respect for elders, the fact that I have to be very respectful to my elders and they have to make me realize that once in a time I'm going to get to this age. So, I have to try as much as possible to treat them the way I want to be treated when I'm there.

This illustrates how cultural values related to helping elders facilitate caregiving roles. Moreover, one knowledge collaborator shared how cultural gender roles often influence beliefs related to caregiving. For instance, Fir shared:

> When [my friend] spoke about dementia, I thought, "Oh god, I better be prepared." Because naturally, with us women, with the [First Nation] women up there, it fell on the women to provide for their parents.

Despite cultural values and roles influencing tendencies to care for loved ones living with dementia, many knowledge collaborators described considerable caregiver stress and burden, often due to a lack of comprehensive support and a large burden of caregiving responsibilities, typically placed on a sole female family member. For instance, Fir shared how her friend, who cared for her mother with dementia, experienced caregiver distress:

> She was double tired, kind of like fussy, and agitated. One time, she snapped at me [at work] and said, "Okay, I told you!" And I just looked at her. And then that's when she finally said, "You know what? I'm going to bust before I even say anything" (…). She said, "My mother has dementia, and I don't know if I can take it anymore."

This illustrates how, despite cultural values underlying caregiving, care partners experience distress associated with caring for loved ones and require additional supports.

In response to increased caregiver stress, knowledge collaborators emphasized the need for caregiver respite, such as in-home support and day programs. For instance, Moon shared how caring for a loved one often requires a circle of respite support:

> When she got back from the doctors and everything and found out, they ended up coming up with a plan within their own little family, like, with her siblings. Her brothers and her, and then they, she got help from, I think it was the nurse at the [local First Nations-led healthcare organization] office. That helped there, and her extended family when they needed a break.

Respite programs and other forms of caregiver support, such as support from extended family, helped to "regenerate" caregivers and helped to support the loved one with aging in place for as long as possible.

Knowledge collaborators also shared that in some cases, values underlying family and community care, such as respect for elders, were beginning to decline in their community. This decline led to increased care partner distress, and at times, created barriers to loved ones aging with dementia in their First Nation community. For instance, Moon shared:

> The biggest, this is like the most saddest thing ever, people always talk about how much, you respect your elders, you be there for your elders, but it seems like a bunch of BS.
>
> Because when it comes down to it, it's rare for people to step up and take care of an elder.

These perspectives illustrate how the preference to age in place can be supported by cultural values and roles related to helping, but negatively influenced by caregiver distress, lack of local supports, and a change in cultural values.

### *Honouring Wise Practices and Expanding Knowledge for Relational Dementia Care*

In addition to culturally safe care and cultural values and roles guiding helping behaviours, knowledge collaborators in both unpaid and paid caregiving roles described additional wise practices for supporting loved ones living with dementia. These practices included supporting the autonomy of the loved one living with dementia by helping to maintain both actual and perceived independence, honouring their preferences regarding transitions in care, and respecting end-of-life decisions. For instance, Maple shared how she honoured her grandmother's wishes to be moved into long-term care:

> She said to me one day, “My girl, it is too hard for you. Put me in the hospital now”. So, when she said that to me, that's when I went and I took her to the hospital.

Although autonomy was not explicitly named, supporting the autonomy of others has been identified as a cultural value in some First Nations communities in Canada (Simpson, 2013), suggesting its relevance to culturally safe care.

Underlying support for autonomy of loved ones living with dementia was an ethic of acceptance. Knowledge collaborators shared instances of accepting the behaviour of the loved one living with dementia. For instance, Donna shared:

> The biggest thing that I don't do when I speak to her is don't say, you remember that. You know, because they say that you make it worse. (…) I have to watch when I speak, because I don't want to say, well, you remember that, don't you? Don't you? But then now I learn to just accept it and just answer them.

Accepting the behaviour of the loved one living with dementia helped to reduce the emotional distress of the loved one, and at times, the care partner as well.

Knowledge collaborators also described the practice of “joining the reality” of their loved ones living with dementia, rather than attempting to correct or redirect their thoughts or

behaviours. This included allowing loved ones to repeat stories or ask the same questions multiple times, gently guiding conversations, and agreeing with their perspective. In one case, “joining the reality” meant supporting the loved one’s belief that they were caring for family members’ children as if they were their own, reflecting a return to an earlier time in their memory. Ed shared an experience where family and paid care partners joined the reality of a loved one living with dementia in long-term care:

> He loved talking about setting the net. He would say, "I'm setting the net. You guys want fish?" We would all say yes. Even the nurses had to say, “Yes, we love fish”. He said, "I'm setting it, and I'm going to be back in the morning with fish."

In this way, family and care partners helped to support the autonomy of the loved one, instead of attempting to change their behaviour or perspective. Joining the reality of the loved one living with dementia was observed to reduce anger and agitation, and at times, help the loved one living with dementia re-join the reality of the loved one. In some cases, however, respecting the autonomy of the loved one was complicated by decreases in judgment and awareness of the disease. These experiences underscore the importance of planning for transitions in care in advance, to fully honour the autonomy of loved ones living with dementia.

Knowledge collaborators also shared instances of using humour to cope with difficult circumstances, including changes in independence. For instance, Poplar shared how his brother, who did not live with dementia, used humour to cope with his changes in independence in long-term care:

> [My brother] was sharp. He lost one leg. The first time, he says, he got a job at IHOP. Then he had the other one taken off, he says, lost my job, couldn't hop anymore.

In some cases, knowledge collaborators developed deep relational bonds with paid care partners, which created space for shared humour and mutual coping in the face of difficult experiences while caring for loved ones with dementia. Notably, most interviews and knowledge-gathering circles included moments of laughter, demonstrating their importance in fostering connection and resilience.

Memory cues were also frequently discussed as helping loved ones recollect memories. Knowledge collaborators shared that they and others brought pictures, videos, music, clothing, moccasins, and other tactile cultural objects to share with their loved ones living with dementia. Nicole shared that tactile objects like moccasins and beading may help loved ones to recall memories over pictures, possibly due to “muscle memory”, and that these efforts should be coupled with acceptance of the loved one’s reality.

Other wise principles of caring for loved ones with dementia included continuity of care partners, care partners who speak Anishinaabemowin or other FNMI languages, using alarm systems to monitor wandering, and person-centred care (e.g., “not painting [everyone] with the same brush”). One community member emphasized person-centred care, given the diversity of FNMI people and levels of acculturation.

Despite practical approaches to supporting loved ones living with dementia, many knowledge collaborators described limitations to their understanding of how best to support their loved ones. For instance, Paul shared that he is unsure how best to support his loved one at times:

> I know living with my brother [who lives with dementia] here gets me upset once in a while because of stress. Because I don't have the knowledge of what to do or what to say to him.

Likewise, knowledge collaborators emphasized the need for paid care partners to also know about dementia prior to providing care. For instance, Jane (First Nations, woman, 67) shared the importance of care providers being aware of memory difficulties impacting awareness of medication usage:

> [My mother] was sent home, and there was home care, but they would ask her, Did you have your medication today? She didn't remember whether she did or didn't. But she would say yes, and they wouldn't check the lockbox, so medication would be missed.

This illustrates the need for in-home care providers to be trained on the impact of dementia on cognition, self-care, and behaviour.

Knowledge collaborators shared the importance of and need for psychoeducation and training programs on dementia for loved ones living with dementia, family and community members, and paid care partners (e.g., personal support workers, nurses, and doctors), including psychoeducation and training programs in rural First Nation communities. Knowledge collaborators described a need for additional education on identifying symptoms, supporting the self-care of loved ones (e.g., feeding and managing food refusal), communication techniques (e.g., redirecting), and how best to balance independence with changes to a loved one's awareness of their disease. For instance, Jane shared how additional access to psychoeducation may help to support better loved ones living with dementia and their care partners:

> I did a presentation in one community, and they asked for it. And it wasn't really what we would normally do, but on [fetal alcohol syndrome], and I had a grandfather say to me, Now he understood what his grandson was going through, because I talked about how they won't recall the incident that got them in trouble for doing a certain activity. They might not recall that that got them in trouble, so they'll repeat it. But I know that

> providing the information was kind of key for him to understand, rather than get frustrated. I think for families, that's key for something like dementia.

This illustrates how, despite some families being aware of some approaches to caring for loved ones with dementia, additional support must be provided.

In one case, a lack of community-based training for family members supporting loved ones with dementia was explicitly connected to barriers to accessing support from family. For instance, Tracy shared:

> Nurses are to go check up on them, but there does not seem to be very much family support. They will be lucky if there is one or two; usually, it only ends up being one taking care of that person, because nobody wants to deal with them. I guess they just get passed around; everybody gets tired of taking care of them. They don't know how to take care of them.

This illustrates how a lack of access to psychoeducation and training may create a barrier to aging in place with dementia.

***Connection to Kinship Networks***

Social connection, such as visiting with family and friends, was described as important for supporting the wellness and sense of belonging of loved ones living with dementia. For instance, social isolation was described by Tracey as contributing to poor emotional wellness for loved ones living with dementia:

> Our oldest elder in the reserve [living in long-term care in a far town], nobody showed up from her family that day on Christmas, and that old lady looked really sad.

Knowledge collaborators shared how social gatherings in the community and within long-term care, such as cultural activities, hiking, outings to the city, group exercise classes, land-based activities, and opportunities for sharing knowledge with younger generations, helped to support

loved ones living with dementia. For instance, Aspen shared that opportunities for loved ones living in long-term care to connect with youth should be prioritized:

> I know my son's school, I don't know if it's cultural, but I think it's in our Seven Grandfather Teachings. His school goes to old folks' homes, and they go and read to the patients there. And I just find it so beautiful. I made Christmas cards for all the people there. I love that. More of that needs to happen.

Importantly, however, opportunities for elders to gather, including those living with dementia, were described as severely limited within communities. Several knowledge collaborators highlighted the need for additional community programs specific to First Nation Peoples, such as support circles, seniors' groups, and counselling for seniors coping with memory loss. Marlene shared that she hopes to see more programs to support elders coping with age-related changes in cognition, including memory loss:

> I don't know what kind of exercises are there for brain. You can't just shake your head. There's things that you can do to create more enlightenment in how to deal with the problems. Because when you start losing them things, those gifts, you start feeling really bad about yourself. And there's nobody counseling us on that. Good thing I have enough, you know, I got good friends. Me and about seven of us, seven other ladies, we get together, it wasn't anything organized, we all ended up getting together, making, bringing food, sit around, talk after.

This illustrates the importance of social connection for people living with dementia, and the need for additional supports to maintain community connection and belonging and facilitate coping with changes to cognition.

Knowledge collaborators also shared the importance of connection to land for loved ones living with dementia, such as fishing, sacred fires, and spending time on the land with family. Connection to land was described as reducing symptom severity, increasing social connection and emotional wellness. Importantly, taking loved ones with dementia onto the land must be balanced with safety and considerations for mobility. Maggie shared how she helped her mother-in-law remain connected to the land, despite being hospitalized for dementia:

> Maggie: I used to take her [a loved one living with dementia living in the hospital] blueberries, break them off, and I let her pick and she can eat it. So, when I took these blueberries, pretend you are picking blueberries.
>
> Brittany: You would bring her branches?
>
> Maggie: Just a small one, not a big one, just enough to hold it and there's blueberries. I gave it to her. And then she took one, and I took one, and then she took another one, and she looked at me. I started laughing.

This act of care illustrates how connection to land can facilitate social connection, despite mobility challenges and hospitalization.

## Discussion

In this thesis, I examined cultural perspectives on the meaning of dementia symptoms, risk reduction, assessment, and post-diagnosis care among FNMI people in Northwestern Ontario, and the individual, interpersonal, and community-level relational supports that support these pillars of care. I also sought to explore how FNMI identity, gender identity, and geographical location of residence influenced these perspectives. The limited participation of Métis and Two Spirit knowledge collaborators suggests that these findings are unlikely to be representative of, nor generalizable to, Métis and Two Spirit people in Northwestern Ontario. Given the limited participation of Métis knowledge collaborators, the absence of Inuit voices, and a small number of Two Spirit collaborators, these findings best reflect the perspectives of First Nations men and women residing in rural and urban communities in Northwestern Ontario.

I constructed 14 themes across the four content areas. Results highlighted that dementia was historically rare or unknown in the First Nation communities visited, but is now becoming more visible, potentially due to an increase in prevalence and awareness. Moreover, factors at the individual, interpersonal, and societal levels were described to increase risk across the lifespan. Approaches to aging well and reducing the risk of dementia highlighted the role of wholistic wellness, access to wraparound care, strong kinship networks, including intergenerational relationships, and opportunities to give back to the community. Results also suggest a wholistic approach the assessment of dementia is necessary, guided by family members and healthcare professionals. Finally, results suggest that approaches to caring for First Nation Peoples living with dementia in Northwestern Ontario should include wraparound, local, relational, and culturally safe care, supported by informed formal and informal care partners, programs to support care partners, and opportunities for people living with dementia to remain connected to community and land.

I also identified 31 individual, interpersonal, and community-level relational supports to support culturally safe dementia risk reduction, assessment, and post-diagnosis care in First Nation communities in Northwestern Ontario. Individual-level relational supports included cultural identity, dementia health literacy, technology access, financial support, connection to land, and roles for retired elders. Interpersonal-level relational supports included connected families and communities, cultural values to promote helping, informal peer networks, intergenerational relationships, healthcare professionals and staff trained in dementia and culturally safe care, and family and community care partners with dementia health literacy. Community-level supports included community-based urban and rural cultural and social programs, Indigenous-led health organizations, band-managed health services, local long-term care and other residential care (including culturally safe options), respite programs, community health fairs, telehealth, dementia continuing education programs for healthcare workers, psychoeducation programs, school programs for youth and elders, local and regional transportation services, spirituality and religious centres, water treatment plants in First Nation communities, and land and waters.

**The Meaning of Dementia Symptoms**

Aligned with previous research, results suggest that dementia is a relatively modern syndrome among First Nations Peoples living in Northwestern Ontario and is becoming more common (Jacklin & Walker, 2020). Although results from the present study reflect a biomedical understanding of dementia as a disease among First Nation Peoples in Northwestern Ontario, previous research has shown that this perspective has generally been uncommon in FNMI communities (Gusul, 2013; Jacklin & Walker, 2020). The contrasting findings in the present study may reflect differences in access to psychoeducation and socioeconomic status (e.g., education), experiences with traditional knowledge, and varying levels of exposure to dementia.

For instance, all First Nation communities visited in this study were road-accessible and located near small towns or a major urban center. Many knowledge collaborators had postsecondary education and experience supporting people with dementia, potentially increasing their exposure to biomedical perspectives through health education. Moreover, many knowledge collaborators described themselves as reconnecting to their culture, sometimes due to the impact of Residential Schools, which may also influence cultural perspectives. Perspectives in more remote or fly-in communities in Northwestern Ontario may differ due to more limited access to healthcare services, education, technology, and dementia psychoeducation resources, and greater access to traditional knowledge.

**Risk Factors and Reduction**

Although I initially applied a Nishnaabe wholistic model of health to identify relational supports, this framework also helped interpret knowledge collaborator-identified risk factors for dementia. The resulting wholistic model of risk factors for dementia reaffirms how broader interpersonal and societal factors may limit or encourage individual-level health behaviours, shaping dementia risk, health, and wellness. For example, in the present study, societal-level factors (e.g., disruption to First Nation ways of being, inaccessible and culturally unsafe healthcare, and air, water, and land pollution) were associated with community-identified individual and interpersonal risk factors (e.g., physical inactivity, poor diet, social isolation, and trauma), all of which are also well-established contributors to dementia risk (Livingston et al., 2024; Sacchetti et al., 2025). These findings further affirm the relevance of Nishnaabe wholistic theory and other ecological approaches to understanding dementia risk among First Nation Peoples in Northwestern Ontario.

Knowledge collaborators consistently shared concerns over the negative impact of stress and trauma (i.e., individual-level factors) on dementia risk in their communities. This perspective

is aligned with other First Nation communities in Canada, who reported trauma as positively associated with dementia risk (e.g., Jacklin & Walker, 2020). Indeed, exposure to early life adversity prior to the age of 18, including emotional, physical, and sexual abuse, emotional and physical neglect, and household challenges (e.g., domestic violence and mental illness in the home) significantly increases the risk of developing Alzheimer's Disease later in life among the general population (e.g., Corney et al., 2022). Moreover, adverse childhood experiences increase the risk of other poor health outcomes among Indigenous Peoples, including heart disease, stroke, diabetes, excessive alcohol use, tobacco use, and depression, some of which are well-established risk factors for dementia (Livingston et al., 2024; Radford et al., 2022; Stefanesu & Hilliker, 2023). While exposure to adverse childhood experiences is higher among First Nation Peoples in Canada than non-FNMI people, protective factors (e.g., cultural identity and connectedness, education, and social support) may reduce the negative impact of trauma on health and wellness later in life (Toombs et al., 2021; 2022). This is further aligned with the results of this research, whereby knowledge collaborators further identified disruption to First Nation ways of being as a risk factor for developing dementia. This suggests that programs and initiatives to reduce the likelihood of adverse childhood experiences or promote protective factors among trauma-exposed First Nations Peoples may decrease the risk of developing dementia in late life.

Knowledge collaborators also widely highlighted the influence of social-level risk factors, including culturally unsafe and inaccessible healthcare services, as a risk factor for developing dementia. This is well-aligned with previous research examining the impact of inaccessible healthcare on dementia risk factors. For instance, difficulty accessing routine healthcare, and an inability to afford prescription medications was associated with increased cardiovascular risk

factors among other First Nations communities in Canada, including smoking status, exposure to second hand smoke, diabetes, high blood pressure, waist-to-hip ratio, stress, depression, and physical inactivity (Anand et al., 2019), several of which are well-supported risk factors for dementia (Livingston et al., 2024). Well-documented barriers to accessing healthcare services among FNMI communities include a lack of coverage, inadequate healthcare, unavailable doctors and nurses, and long waiting lists (Loppie & Wein, 2022). Similarly, healthcare systems with systemic and personal racism serve as an additional barrier to accessing care (e.g., Loppie & Wien, 2022; Turpel-Lafond, 2020), which is consistent with findings from this study.

Knowledge collaborators described the impact of disruptions to First Nation ways of being, including loss of cultural values, engagement with traditional foods, and intergenerational relationships, on increasing the risk of developing dementia. Likewise, changes to Indigenous ways of being were identified as risk factors for dementia among other Indigenous Peoples (Jacklin & Walker, 2020). Cultural identity relies on connection to culture, such as access to traditional teachings and knowledge through intergenerational relationships, and environments to express culture within society (e.g., King et al., 2009). Notably, connection to culture has been identified as a protective factor for several health conditions, including a reduced prevalence of type 2 diabetes, heart disease, physical inactivity, substance use difficulties and poor mental health among FNMI people in Canada and Indigenous people in the United States (e.g., Auger, 2016; Ironside et al., 2020), several of which are risk factors for dementia. Thus, disruptions to First Nations' ways of being, a societal-level risk factor, may influence dementia risk indirectly through individual-level risk factors, such as alcohol use.

Air, water, and land pollution, a societal-level risk factor, was also identified as a risk factor for dementia, and associated with changes to diet, an individual-level factor. Changes in

diet due to colonization and pollution have likewise been identified as risk factors for dementia among FNMI populations in Canada and Māori (Jacklin & Walker, 2020; Menzies et al., 2022). Likewise, environmental factors, including extreme heat, have been proposed to influence dementia risk by disrupting access to traditional foods (Henderson et al., 2024), reducing opportunities to access healthier diets, connect to traditional territories, and engage in physical activity. Inability to engage in land-based cultural practices has also been associated with feelings of depression, a risk factor for dementia (Livingston et al., 2024), among Inuit (Cunsolo Willox et al., 2012). Additionally, residing near areas of ecosystem degradation caused by resource development has been linked to psychological distress among Aboriginal Peoples in Australia (Speldewinde et al., 2009). This illustrates how social-level risk factors can further influence individual-level factors.

Knowledge collaborators emphasized the need to care for wholistic wellness to reduce the risk of dementia, such as through cognitive stimulation, land-based activities, reconnecting to cultural identities, land-based diets, and traditional medicines. Multi-domain interventions that include similar factors indeed help to improve cognitive function and may help to reduce the risk of dementia among elders, including those at-risk for developing dementia (e.g., Castro et al., 2023). However, access to these interventions often relies on community-level relational supports, including local healthcare infrastructure and funding for community-based programming, which were described as limited in this study. Traditional medicines, including Boreal forest plants, may also help to reduce the risk of dementia through their antidiabetic qualities (e.g., Eid & Haddad, 2014). Accessing these medicines, however, requires access to clean and unpolluted land, which was also described as a growing concern in this region. Moreover, connection to culture has been associated with reduced prevalence of type 2 diabetes

(Oster et al., 2014), increased physical activity, and healing from trauma (Gone, 2013), providing support for the role of reconnecting to cultural identities and reducing the risk of dementia. These findings further support community-identified approaches to reducing the risk through addressing individual and societal-level risk factors for dementia in Northwestern Ontario.

Cultural continuity through intergenerational relationships between elders and youth addressed several identified risk factors for youth and elders, including facilitating the transmission of cultural values and a sense of purpose, and engagement with ceremonies, music, language, education, and traditional medicine. Cultural continuity, fostered through intergenerational relationships, is determinant of health for FNMI Peoples (e.g., Loppie & Wien, 2022), and is indeed associated with several positive health outcomes across the lifespan, including improved self-esteem, cultural identity, sense of belonging and purpose, stress coping, reduced prevalence of type 2 diabetes and substance use difficulties, healing from trauma, grief, and loss, and healthy and strong communities and families (e.g., Auger, 2016; Cornect-Benoit et al., 2020). Importantly, meaningful opportunities for elders to engage with youth rely on developing community-based programs with appropriate government funding (Cornect-Benoit et al., 2020), further illustrating the need for initiatives that address individual, interpersonal, and societal-level risk factors.

Local and virtual wraparound services (e.g., culturally safe mental and physical health services and community-based programs) were described as helping to address identified risk factors by supporting emotional and physical wellness, reducing social isolation, and fostering intergenerational relationships between elders and youth. This finding is supported by previous research conducted with other First Nation communities across Canada, which found that self-reported health was associated with civic engagement and organizational membership (e.g.,

church groups, Native Women's Group, council membership) (Yeung et al., 2021). Further, social connection is significantly associated with reducing risk for dementia in late life among the general population (Sacchetti et al., 2025), providing further support for local and virtual community programs.

Connected and caring families and communities were described as central to aging well and reducing the risk of dementia. Indeed, connection to family and engagement in grandparent roles were described as supporting physical health, emotional well-being, and motivation for self-care among older Indigenous Peoples globally (Quigley et al., 2020). Similarly, communities that offer support, such as transportation services, were associated with increased social connection, memory recollection, and a stronger sense of belonging among older Indigenous adults globally (Quigley et al., 2020). Communities with greater trust and social support also evidence lower cardiovascular risk factors (Anand et al., 2019), reinforcing the importance of strong family and community ties in reducing dementia risk in First Nation communities in Northwestern Ontario.

Knowledge collaborators further emphasized that connection to land and waters promotes aging well and addresses several identified risk factors for dementia. Likewise, among First Nations youth in Canada, connection to land has been identified as a determinant of health through facilitating cultural learning, engagement with traditional skills, preparing traditional foods with Elders, and promoting overall well-being (Lines et al., 2019). Moreover, connection to land has also been associated with physical activity, access to traditional foods to support healthy diets, and cognitive stimulation among Labrador Innu elders (Pace, 2020), which are supported risk and protective factors for dementia (Livingston et al., 2022). Moreover, engagement with traditional lands is also described as contributing to healthy aging among

Indigenous Peoples globally (Quigley et al., 2020). Importantly, given proximity to polluted lands has been associated with psychological distress, supporting a connection to land further relies on addressing societal-level risk factors.

Opportunities to help others in the community, such as preparing meals for others, leading programs and committees, and supporting peers, were also associated with community-identified risk factors for dementia. Interestingly, community involvement (e.g., volunteering) has been associated with reduced likelihood of high central adiposity, elevated blood glucose levels, and metabolic syndrome among middle-aged adults, and hypertension among elders (Burr et al., 2015). Moreover, women who volunteer have a lower risk of cardiovascular death (e.g., heart attack or stroke) (Burr et al., 2018), suggesting that volunteering in the community may impact dementia risk through cardiovascular risk factors. In addition, helping others also reduces the risk of developing depression, a risk factor for dementia, through increasing life satisfaction (Cheng et al., 2024). Lastly, formal volunteering roles are also associated with higher levels of cognitive functioning (e.g., working memory and processing), particularly among women and individuals with lower education (Proulx et al., 2018). Helping others may facilitate cognitive functioning through exposure to complex tasks, learning, social engagement, and physical activity (Proulx et al., 2018). Moreover, helping others may improve overall health, lower cardiovascular risk factors, and reduce the risk of cognitive decline through reducing systemic inflammation (Bell et al., 2022; Schmidt et al., 2002). For instance, elevated C-reactive proteins, a biomarker for systemic inflammation, have been associated with type 2 diabetes, cardiovascular disease, vascular dementia, and Alzheimer's disease (Schmidt et al., 2002), whereas normal levels are associated with not smoking, high physical activity, and having normal body mass index (Bell et al., 2022). Collectively, these findings support the positive

influence of helping others in reducing the risk of dementia in First Nation communities in Northwestern Ontario.

**Assessment**

Family members were often the first to recognize changes in their loved one's socialization, cognition, emotions, and behaviour, which prompted seeking an assessment through a healthcare provider. This contrasts with other Indigenous populations, such as those in Australia, where healthcare providers are typically the first to notice symptoms (Bryant et al., 2021). In other research, up to 50% of dementia cases were first recognized and documented in primary care settings (Bello-Has et al., 2014). This finding is particularly important given the central role of early diagnosis in dementia care. Early diagnosis of dementia is principal in providing appropriate intervention and support services, educating loved ones and their families on expectations, progression, and prognosis, and making end-of-life decisions while cognitively able (Dal Bello-Has et al., 2014). For instance, early dementia diagnosis allows informal care partners to better adapt to a caregiver role, leading to more competent care and fewer psychological problems (de Vugt & Verhey, 2013). Despite this, individuals may wait up to three years before seeking an assessment (Leung et al., 2011). Delayed diagnosis can lead to delayed access to treatment, services, disease management education, and information, increased caregiver distress (e.g., feelings of uncertainty, depression, stress), and an inability to plan and make decisions (e.g., Dal Bello-Has et al., 2014; de Vugt & Verhey, 2013). Delays in diagnosis may be due to a lack of dementia health literacy and community awareness of understanding dementia (e.g., Bryant et al., 2021; Meng Lee et al., 201), which was also somewhat evidenced in the current study. Thus, given the important role of family members in identifying early symptoms among First Nation communities in Northwestern Ontario, increased psychoeducation on signs and symptoms is imperative.

**Post-Diagnosis Care**

Knowledge collaborators emphasized the desire to age in place, which relied on access to local wraparound care services and several relational supports. Aligned with other Indigenous communities (Jacklin & Walker, 2020; Racine et al., 2021), family caregiving was frequently mentioned as the primary source of support when aging in place and supplemented by a community of care. There are several documented benefits of aging in place for Indigenous Peoples, including retaining connections to family, community, land, traditional ways of life, and places of worship, which can facilitate social engagement, healthy diets, cognitive stimulation, memory recollection, cultural identity, spiritual wellness, and physical activity. Further, aging in place can ensure elders retain opportunities to contribute to their communities, further supporting a sense of purpose (Bartlett et al., 2012; Jacklin & Walker, 2020; Pace, 2020). Moreover, aging in place may reduce mortality rates, given that institutionalization can double mortality rates among people living with dementia (Jacklin & Walker, 2020).

Several wholistic relational supports were described as necessary to support First Nation families and communities in caring for a person living with dementia in Northwestern Ontario, such as local healthcare services, culturally safe care, and respite programs. Consistent with these findings, aging in place in other Indigenous communities relies on improved home care, supporting traditional caregiving values, culturally safe care from paid service providers, and Indigenous-led residential care that reflects Indigenous culture, language, and values (e.g., Jacklin & Walker, 2020). Despite this, there is a considerable lack of available wraparound services in many Indigenous communities, including a lack of paid support workers, respite services, financial support to mitigate transportation costs, and culturally safe care (Racine et al., 2021), which was frequently discussed in more rural communities visited in the present study.

Such considerations must be made when considering wraparound care services for First Nation communities in Northwestern Ontario and beyond.

The results of this study also highlight that providing care for a loved one living with dementia increases distress among informal care partners. Heightened distress and changes in health and cognition associated with caring for family members living with dementia are well-documented in the literature (see Fonareva & Oken, 2014, for a review). Pearlin et al. (1990) advanced a conceptual framework caregiver distress, which articulated how stress is due to the background and context of the carer (e.g., socioeconomic status and resources), stressors (e.g., caregiving demands), mediators of stress (e.g., coping resources and social supports), and outcomes or manifestations of stress (e.g., depression and physical health problems). Interventions and programs to support care partners often focus on mediators of stress, such as education/skill-based interventions (e.g., to increase knowledge of dementia and coping skills), support and counselling interventions (e.g., individual and group therapy), and physical activity-based interventions (e.g., to promote physical activity and exercise), which are effective at reducing carer burden (Chiao et al., 2015). However, the background and context of the carer may influence the availability of such programs and the appropriateness of the program. Indeed, in the present study, knowledge collaborators from more rural communities described increased barriers to accessing relational supports for care partners, including programs and interventions.

Aligned with Nishnaabe wholistic theory, individual, interpersonal, community and societal relational supports may also influence the extent of caregiver distress. Gaugler et al. (2023) recently proposed a model of dementia caregiver health that reflects societal and community relational supports, including economic stability, educational access and quality, healthcare access and quality, neighborhood and built environment, and social and community

support, and mechanisms in which such factors influence caregiver health, including social isolation, health literacy, and financial strain. For instance, a lack of educational access and quality can negatively impact health literacy, increasing distress due to a lack of knowledge of the disease, and negatively impairing the ability to access services (Gaugler et al., 2023). The health of caregivers may be further impacted by fragmented and culturally unsafe healthcare systems (Loppie & Wien, 2022). Indeed, Indigenous care partners report a lack of access to support services, racism and discrimination, which creates distrust within mainstream healthcare (Racine et al., 2021), providing an additional barrier to supporting care partners.

Results also emphasized the importance of connection to community and land for people living with dementia. Creating and maintaining roles in the community has been rated highly among people living with dementia (e.g., Cohen-Mansfield et al., 2006). Notably, social relationships can foster a sense of self and identity, which has been identified as the most critical aspect of life for people with moderate to severe dementia (Perkins et al., 2015). Programs that support intergenerational relationships involving youth and people living with dementia have been shown to support a sense of self, reduce anxiety and agitation, and increase physical activity, even in later stages of dementia (Galbraith et al., 2025). Such programs have included crafts, music, singing groups, education programs where elders teach children, storytelling through oral histories and reminiscence, and recreational activities such as gardening, bingo, woodworking, and nature walks (Galbraith et al., 2015). For example, an intergenerational choir involving people living with dementia, care partners, and youth in Canada improved cognitive function among people living with dementia by reducing negative affect (McDowell et al., 2022). Intergenerational programs with youth and elders, including land-based programs, have also been emphasized in supporting brain health among First Nations in Ontario (Cornect-Benoit

et al., 2020). These findings highlight the importance of developing intergenerational programs, including land-based programs, for First Nations peoples living with dementia in Northwestern Ontario and beyond.

**Gender and Geographic Influences**

Gender primarily influenced perspectives on providing care to loved ones living with dementia. Knowledge collaborators described how the assumption of caregiving was often placed on women, which one knowledge collaborator described as a cultural role. Indeed, gender-based roles in caring for loved ones living with dementia are well-documented, where women are more likely to provide care (e.g., Alzheimer's Society of Canada, 2022), including within Indigenous communities (e.g., Jacklin & Walker, 2020). Notably, women care partners may be more likely to experience greater caregiving challenges, psychological stress, family conflicts, guilt, and symptoms of depression, and lower quality of life and sense of coherence than men (e.g., Xiong et al., 2020). Providing care to a loved one with dementia can negatively impact food security, financial stability, and lead to difficulties managing work responsibilities and reduced income, further impairing socioeconomic status (Gaugler et al., 2023). Many of these outcomes are also risk factors for developing dementia, suggesting caregiving may perpetuate an intergenerational cycle of dementia risk factors, predominantly among women.

While geographical location did not influence care perspectives, it did influence the availability of wholistic relational supports to support identified approaches to care. Rural residents described greater barriers related to cost and availability of transportation, limited local and culturally safe healthcare, insufficient long-term or residential care options, and a lack of community-based programs, psychoeducation programs and workshops. To protect confidentiality, this study did not map relational supports by specific communities; however, differences were observed. For example, one rural community was close to an urban center,

while another was several hours away. The distance from the urban city appeared to increase the number of barriers to accessing care and reduce the availability of relational supports.

**Study Strengths and Limitations**

The community-engaged approach to this research is a substantial strength. Community-engaged dementia research with Indigenous communities can improve the relevancy and usefulness of the results. Community-engaged research (e.g., the extent of community involvement in the research approach and analysis) has been associated with greater context relevance of research outcomes (Kjerland et al., 2024). Context relevance is defined as the benefits, usability, and respectful conduct of research from the perspective of Indigenous communities (Kjerland et al., 2024). The present research used a community-engaged approach by collaborating with a First Nations-led health organization to determine the research objectives, approach, and analysis. Moreover, adherence to OCAP™ principles (e.g., Schnarch, 2004) further ensured that this research aligned with community priorities and needs. The regular contact with the community advisory committee helped to ensure the research remained responsive to community needs and priorities. For instance, the community partner indicated a need for psychoeducation presentations on dementia within local First Nation communities, which I developed and implemented. Initial feedback from the community partner suggests that the findings of this research will be helpful in health programming, psychoeducation efforts, and funding applications. Future meetings with the community partner will seek to obtain further insights into the relevance and outcomes of this research.

My research approach also sought to promote brain health in the process and outcome. Knowledge gathering circles sought to strengthen relationships within the community, thereby helping to reduce social isolation, and included healthy foods, including foods associated with improved brain health. I also sought to provide psychoeducation on dementia, including

symptoms, risk factors, and approaches to risk reduction, to support dementia health literacy in the region. The involvement of Elders within each community also helped to support traditional roles within each community, which may help to provide a sense of purpose and meaning. Importantly, the impact of the research on promoting brain health was not evaluated, and thus, definite conclusions cannot be made.

Feedback from knowledge collaborators on the research approach was positive. They expressed appreciation for the involvement of ceremony and Elders at the knowledge gathering circles, the use of a relational approach, the option to attend a knowledge gathering circle or interview, and the presence of a welcoming interviewer with clear questions. Knowledge collaborators recommended that future research in the community include people living with dementia, offer the option to meet in the knowledge collaborator's home, provide more psychoeducation on dementia, and visit with a broader range of communities.

There are also several limitations to this research. First, no people living with dementia were involved in this study as knowledge collaborators or community advisory committee members. Notably, despite the inclusion criteria being inclusive to people living with dementia, we were unable to recruit people living with dementia. There is a widespread acceptance of the importance of research that includes the perspectives and experiences of people living with dementia. Such inclusion helps to improve the relevance, effectiveness, and quality of policies and services for people living with dementia (e.g., Miah et al., 2020). Moreover, involvement of people living with dementia in research can facilitate a sense of purpose and satisfaction, identify meaningful results, validate the researcher's interpretations, and ensure that dissemination materials are accessible to people living with dementia and their care partners (e.g., Miah et al., 2020). Despite the lack of people living with dementia, several knowledge collaborators had

living and lived experience of caring for a loved one living with dementia, which enhanced the insights and relevance of the findings.

Secondly, it is plausible that this study excluded potential knowledge collaborators who could not participate due to challenging health conditions or caregiving responsibilities. Notably, 12 individuals who initially registered for the study later cancelled, most often citing health-related reasons, including hospitalizations and the need to care for a partner with declining health. This suggests that the perspectives shared in this study may underrepresent the voices of those most directly impacted by the daily realities of caring for elders, including those living with dementia. As a result, the findings may not be fully generalizable to all First Nations peoples in Northwestern Ontario, particularly those experiencing complex health or caregiving circumstances. Future research should consider more flexible participation options, including home visits, to better include these voices.

A final limitation is that I independently conducted the data analysis and interpretation. Multiple coders in qualitative research help to minimize differences in interpretations and coding, improve the trustworthiness, rigour and transparency of coding and results, and increase confidence in the evidence-base (O'Connor & Joffe, 2020). Despite the value of the analyst's interpretation of data within qualitative research, multiple analysts help ensure that the meaning extends beyond the perspective of a sole researcher. Despite this, insisting on the use of multiple analysts is often criticized by qualitative researchers for contradicting the interpretative approach to qualitative research, which tends to hold epistemological positions that welcome active personal engagement with the data and do not work towards objectivity (O'Connor & Joffe, 2020). Moreover, obtaining objectivity while seeking out latent themes may not be possible, given that latent meanings are often constructed through conceptually engaging with the data

personally, requiring in-depth interpretation (O'Connor & Joffe, 2020). Further, using multiple analysts does not necessarily mean that data would be interpreted the same way beyond the research team (Sweeney et al., 2012). Instead of using multiple analysts, and to respect the collaborative nature of knowledge, I sought to obtain reliability through producing thick description with many samples of raw data in the results, attended to deviant cases, and asked knowledge collaborators and the community advisory committee to validate the legitimacy of analytic interpretations (O'Connor & Joffe, 2020).

**Study Implications and Future Research**

These findings have important implications for developing and delivering dementia-related psychoeducation resources in First Nation communities in Northwestern Ontario. Knowledge collaborators, including those currently caring for loved ones living with dementia, described dementia as a frightening disease and often expressed a need for more information to help reduce risk and provide appropriate care. This finding is consistent with previous research that has identified limited dementia health literacy in many First Nation communities in Canada (Public Health Agency of Canada, 2021). Participants expressed interest in general educational materials and those reflecting First Nation worldviews and lived experiences. This points to a clear need for greater access to dementia psychoeducation. Knowledge collaborators may benefit from various formats, including in-person gatherings, presentations, printed handouts, and online materials, all tailored to the specific context of First Nation communities in Northwestern Ontario. These efforts should be guided by a two-eyed-seeking approach (Wright et al., 2019), which brings together Western biomedical knowledge and First Nation ways of knowing in a respectful and balanced way.

The findings of this thesis suggest that dementia risk reduction programs and interventions for First Nation communities should align with cultural values, goals, and perspectives. Self

Determination Theory, a well-established framework in behavioural medicine, highlights the importance of supporting basic psychological needs such as autonomy, competence, and relatedness to promote motivation and well-being (Grodesky et al., 2006). The theory describes motivation along a continuum from amotivation through various levels of extrinsic motivation to intrinsic motivation, which is associated with engaging in behaviours because they are personally meaningful (Grodesky et al., 2006). Health behaviours that connect to personal values, such as cultural reconnection or engagement with youth, are more likely to be sustained than those driven by external pressures or rewards (Grodesky et al., 2006). Accordingly, culturally grounded risk reduction strategies, including psychoeducation resources, that integrate cultural perspectives may be more effective for First Nation peoples in Northwestern Ontario. Future research should explore these approaches in greater depth.

Despite the promise of individual-level efforts to address dementia risk in First Nation communities, the results of this research suggest that these efforts must be coupled with initiatives and programs at the societal level. Findings indicate a wholistic model of dementia risk, with risk factors and relational supports, or protective factors, interacting at individual, interpersonal, community, and societal levels. Importantly, there are likely several more societal, interpersonal, and individual-level factors that are meaningful to further understand the increase in the prevalence of dementia in FNMI communities. For instance, colonial policies and ideologies, such as white supremacy and government policies, continue to affect healthcare access and funding, contribute to environmental harm, and disconnect FNMI people from culture, land, community, and identity. Such systems further increase the likelihood of individual-level risk factors for dementia, including chronic disease, trauma, psychiatric disorders (e.g., depression), and substance use (Loppie & Wien, 2022). While promoting

individual behaviour changes remains important to influencing dementia risk, focusing only on individuals overlooks broader systemic issues that greatly shape the health and wellness of FNMI people. Therefore, individual-level programs are unlikely to be effective in the long term without a coupling with systemic changes (e.g., program funding, transportation infrastructure, culturally safe healthcare).

This research highlights important considerations for creating culturally grounded assessment tools for First Nations peoples in Northwestern Ontario and nationally. Knowledge collaborators described many wholistic risk and protective factors for dementia (e.g., trauma, kinship relationships, access to healthcare) and perspectives on post-diagnosis care (e.g., access to culturally safe care, caregiver distress) that are valuable in developing culturally and contextually responsive care for the needs of First Nation elders. Combining these with Western frameworks could provide a fuller picture of risk and needs to inform risk reduction and comprehensive care planning better. There are already examples of culturally specific tools developed for Indigenous Peoples, such as the Good Life Tool in Australia, which includes community-identified components of quality of life (e.g., connection to land and community) (Gilchrist et al., 2023). Similarly, work with Māori communities in New Zealand is underway to build cognitive assessments that reflect their unique perspectives on aging, cognition, relationships, identity, and place (Menzies et al., 2022). Given that assessment tools guide risk reduction efforts and care planning, they must reflect First Nations' views on aging and dementia to help improve culturally safe and effective care. Future research should work towards developing culturally grounded wholistic dementia assessment tools for FNMI communities.

Culturally safe care, particularly as it pertains to post-diagnosis care, should also be regionally and nationally prioritized. Behavioural and psychological symptoms of dementia,

including distressing perceptions, thought content and mood, and behaviour (e.g., aggression and apathy), occur in over 90% of people living with dementia (Kolanowski et al., 2017; Tampi & Jeste, 2022). Such symptoms are associated with decline in function, greater morbidity and mortality, risk of physical abuse, poor quality of life, caregiver burden, and high risk of nursing home placement (Kolanowski et al., 2017; Tampi & Jeste, 2022). The presence and severity of behavioral and psychological symptoms are typically associated with patient factors (e.g., premorbid mental health concerns, severity of dementia, acute medical conditions, sleep difficulties, boredom, and loss of control or purpose), caregiver factors (e.g., stress, burden, self-care techniques, depression, lack of education on dementia, communication issues), and environmental factors (e.g., over or under cognitive stimulation, safety issues, lack of activity or structure, and lack of established routines) (Kolanowski et al., 2017; Tampi & Jeste, 2022). Pharmacotherapy and psychosocial interventions (e.g., massage and touch therapy, music therapy, outdoor activities, exercise, animal-assisted interventions, light therapy, reminiscence therapy) effectively reduce the presence and severity of behavioural and psychological symptoms of dementia. However, in the present research, severity and presence of symptoms were associated with environmental and caregiver factors, including access to culturally safe care. It is plausible that culturally safe care helps reduce the severity and presence of symptoms through environmental factors, including access to culturally meaningful activities, and caregiver dynamics, including the presence of culturally familiar caring relationships. However, there is presently no available research that examines the impact of culturally safe care on the severity and presence of dementia symptoms. Given the limited discussion within this research, future research is needed to examine the impact of culturally safe care on dementia symptom severity and progression.

These results also have implications for developing models for culturally safe dementia-friendly communities in First Nation communities in Northwestern Ontario and beyond.[7]. Results emphasized the importance of connected families and communities, culturally safe dementia care, support for care partners, psychoeducation for care partners, and connection to community and land. Alzheimer's Disease International (n.d.) defines dementia friendly communities as a "place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognize their full potential" (para 6). The four essential components of dementia-friendly communities include the inclusion of people living with dementia, physical and social environments that are appropriate to the needs of people living with dementia, businesses and organizations that develop dementia friendly approaches and strategies, including within healthcare settings, and cross-sectoral support and collective action to promote change (Novak et al., 2020). Dementia friendly communities help to empower people living with dementia and reduce the social stigma of dementia through engaging people living with dementia to change policy, practice, and services, investing in volunteers and staff to promote awareness and improve skills, creating environmental adaptations, and better supporting caregivers (Novak et al., 2020). Given many similarities in the meaning of aging well and post-diagnosis care among FNMI communities (Jacklin & Walker, 2020; Quigley et al., 2022), future research should work towards developing a FNMI model of dementia friendly communities that can be further modified at the community level to reflect a distinctions-based approach that is culturally and contextually responsive. Such

[7] My thinking around the development of a model for dementia friendly First Nation communities was informed by a conversation with Dr. Sharlene Webkamigad, who first described this concept to me in 2024.

a model may further help FNMI advocate for federal funding to support identified needs to facilitate adequate culturally safe post-diagnosis care in their communities.

Despite the importance of dementia friendly communities, several barriers to culturally inclusive dementia friendly communities include dementia stigma due to racism, low dementia health literacy, lack of culturally safe health care, lack of funding for cultural dementia friendly initiatives, limited culturally appropriate career supports, language and financial barriers, and lack of access to transportation and adequate housing (Shatnawi et al., 2023). In comparison, several facilitators of culturally inclusive dementia friendly communities include culturally appropriate dementia education and training interventions, culturally appropriate assessments, bilingual staff, programs that reduce social and cultural isolation, improving transportation accessibility, and securing sufficient funding for cultural inclusivity in dementia friendly communities (Shatnawi et al., 2023). These factors must be addressed when developing models and initiatives to support dementia friendly FNMI communities.

Finally, the results of this research have international implications. Notably, despite the large diversity between and within Indigenous populations globally, several perspectives of culturally safe risk reduction were noted, including maintaining spirituality, emotional wellness, cognitive engagement, sense of purpose, connection to land, accessing traditional foods, and maintaining connections to identity, family, community, culture, spirit, and land (Quigley et al., 2022). Likewise, similar challenges were described to aging well, including a lack of access to culturally safe health programs and services, housing, transportation, and the presence of trauma, loss of language, traditions, and culture (Quigley et al., 2022). Accordingly, the development of international guidelines and policy towards reducing the risk of dementia and improving post-diagnosis care among Indigenous Peoples globally may be effective in better advocating for

identified needs. Such guidelines can be modified at the national, provincial/state, and regional levels to ensure a distinctions-based approach responsive to community-identified needs.

## Conclusion

The current and projected prevalence and incidence of dementia are higher among FNMI people in Canada than non-FNMI people (Alzheimer's Society of Canada, 2024). First Nations peoples have distinct perspectives, needs, and resources for dementia risk reduction, assessment, and post-diagnosis care. As such, culturally safe dementia initiatives, such as psychoeducation, assessment tools, risk reduction programs, and dementia friendly community models, must reflect these perspectives to be most responsive and culturally and contextually relevant. When properly funded and resourced, such approaches may help reduce the risk of dementia, improve assessment services, and post-diagnosis care. Such initiatives and federal funding initiatives are necessary to fully and meaningfully realize the priorities set forth by Canada's dementia strategy for FNMI people (Public Health Agency of Canada, 2019).

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**Appendix A: Recruitment Social Media Poster**

## Appendix B: Letter of Information and Consent to Participate in a Research Study

### Letter of Information and Consent to Participate in a Research Study

### Anishinabek Brain Aging in Older Adults Study

**Principal Investigator:** Christopher Mushquash, Ph.D., C.Psych, Lakehead University

**Co-Investigator:** Brittany Skov

*In collaboration with Dilico Anishinabek Family Care*

Dear Potential Participant/Knowledge Contributor:

You are invited to contribute to a research study entitled the Anishinabek Brain Aging in Older Adults Study that is being conducted by Brittany Skov, Dr. Christopher Mushquash, and Dilico Anishinabek Family Care.

As a First Nations, Métis, or Inuit adult who has an interest in, living experience of, or experience supporting older adults with changes in brain health in older age, your experiences and perspectives may help us better understand brain aging perspectives and existing strengths in our communities to promote brain health for older adults.

Brittany Skov is a graduate student in the clinical psychology program at Lakehead University, supervised by Dr. Christopher Mushquash, C.Psych. Dr. Mushquash is an Associate Professor in the Department of Psychology at Lakehead University. Alexa Curci is a research assistant on this study. If you have further questions about this study, you may contact Brittany Skov at 905-988-3229 or by email at surg@lakeheadu.ca.

Taking part in this study is voluntary. Before you decide whether you would like to take part in this study, please read this letter carefully to understand what is involved. After you have read the letter, please ask any questions you may have. Please take as much time as you need to decide if you'd like to participate.

**Community Partner: Dilico Anishinabek Family Care**

This project is partnered with Dilico Anishinabek Family Care, who provides leadership on the project development and management. Dilico Anishinabek Family Care will have ownership and access to the data, including personal information. Personal information will not be directly connected to the information you share. You are free to refuse to participate or to withdraw from the study at any time without changing in any way the quality of care that you receive.

**Funding Sources**

This study is funded by Mitacs, Mental Health Research Canada, the Heart & Stroke Foundation, Brain Canada, the Canadian Institute of Health Research, and Psi Chi: The International Honor Society of Psychology.

**What is the purpose of this study?**

The number of First Nations, Métis, and Inuit older adults living with brain health difficulties (e.g., unexpected, age-related, progressive, and irreversible cognitive decline, such as memory loss) is increasing in Canada. Sometimes, these symptoms are common experiences related to aging, but sometimes these symptoms can be part of a disease that is diagnosed as dementia by a physician.

Healthcare organizations and governments need to make sure that brain health efforts, including prevention, assessment, and post-diagnosis care when someone has a disease, respect the unique needs of First Nations, Métis, and Inuit peoples.

Understanding brain health perspectives and support systems among First Nations, Métis, and Inuit peoples in Northwestern Ontario may help Dilico Anishinabek Family Care better support older adults at risk for, or living with, changes to brain health (e.g., memory loss).

**Who can participate in this study?**

You are being asked to participate in this study because you are a First Nations, Métis, or Inuit adult, aged 18+, with an interest in, living experience of, or experience supporting others with changes to brain health in older age (e.g., unexpected age-related, progressive, and irreversible cognitive decline, such as memory loss).

**What information will be collected?**

If you consent to voluntarily participate in this research, you will be invited to share your stories, perspectives, and experiences with brain health changes in older age (e.g., memory loss), brain health promotion, assessment, and post-diagnosis care, and existing strengths in the community that support brain health care for older adults. You will be invited to bring in images, or meaningful objects, that depict something that helps you age well in Northwestern Ontario. You will also be asked a short series of demographic and brain aging questions. You can choose to skip any questions you do not wish to answer.

**What is requested of me as a participant?**

Your participation will include attending a 3.5-hour sharing circle, and a feast, OR a 1-hour to 1.5-hour interview. It will also include a short questionnaire.

Sharing circles will be facilitated by Brittany Skov and an Elder or Knowledge Holder associated with Dilico Anishinabek Family Care and will follow cultural protocols.

Sharing circles will be held in the City of Thunder Bay and the district of Thunder Bay, including on-reserve. Up to 10 knowledge contributors/participants will attend each sharing circle.

Interviews will be facilitated by Brittany Skov, with the option of having an Elder or Knowledge Holder attend. A food and beverage gift card will be provided. Interviews will be held in a semi-

private location in the City of Thunder Bay and the district of Thunder Bay, including on-reserve, at a location agreed upon by you and the research team.

You will be invited to bring any type of image or object, such as a painting, drawing, or photograph of anything that helps you age well in Northwestern Ontario (e.g., a place or an activity). Images and objects will be shared at the sharing circle or interview. A photo or object is not required. Please do not share photos or objects that may identify other people without their consent.

You will also be asked to complete a short in-person paper questionnaire. You will be asked to provide answers to questions regarding demographic variables (e.g., age, level of education, current income, employment, sex and gender, First Nations, Métis, or Inuit ancestry, geographical location), history of brain health changes in older age (if applicable), and perspectives on brain health. You may decide to not answer any question.

Some individuals may receive assistance from a legal or substitute decision maker in making healthcare and other decisions. If a legal or substitute decision maker has been appointed, they must provide signed informed consent in person at the sharing circle or interview. If the legal decision maker does not provide informed consent (in-person) the participant will be unable to participate. The research team will also obtain the participant's permission or assent in person.

Care partners, including legal and substitute decision makers, are welcome to attend the sharing circle or interview to provide support. Care partners and decision makers attending the sharing circles or interviews who wish to participate are required to sign an informed consent letter and complete the questionnaire.

**What are my rights as a participant?**

We value and respect your rights as a knowledge contributor/participant in this study. You are under no obligation to participate in this study. You are free to withdraw at any time without prejudice to pre-existing entitlements and services provided by Dilico Anishinabek Family Care. You will be given, in a timely manner throughout the course of the research project, information that is relevant to your decision to continue or withdraw from participating.

**What are the risks?**

There is a possibility that answering some of the questions and hearing other knowledge contributor/participant's perspectives may make you feel upset and cause relational distress. There is a potential for sharing information related to elder abuse. There is a small burden of time associated with attending the sharing circle or interview. If you feel upset at any time completing the study, please contact:

Dilico Anishinabek Family Care Health and Wellness Centre

17 Court Street South

Thunder Bay, ON, P7B 0E8

Phone: (807) 626-5100

Fax: (807) 626-7999

Toll-Free Fax: 1-855-626-7999

https://www.dilico.com/

If you have research-related questions, please contact Dr. Mushquash by phone at (807) 343-8239 or by email at chris.mushquash@lakeheadu.ca.

**What are the benefits?**

There are minimal individual benefits to participating in this study. You may find it satisfying to contribute to research programs and/or contribute to our understanding of brain health perspectives and support systems among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

**Honorarium**

To honor your contributions to this study, you will receive a $75 Mastercard gift card. A meal is also provided.

**How will my privacy be protected?**

**Anonymity:** Your individual information will not appear in any reports or publications. All information will only be used when it is combined with other participants' information, without your name or other information that would identify you.

Some knowledge contributors/participants may wish to include their name in published research reports, whereas others may wish to use a fake name (i.e., a pseudonym). You will have the opportunity to indicate your preference on the consent form.

Several steps have also been taken to protect your confidentiality.

**Confidentiality:** All information obtained is strictly confidential. The information you provide will only be accessed by designated members of the research team. All Dilico staff are trained to maintain your confidentiality and have signed confidentiality agreements.

Due to the nature of sharing circles (e.g., group format), we are unable to guarantee confidentiality. However, the research team will remind and invite participants to respect each other's privacy.

Consistent with Lakehead University's policy on research data storage, paper copies of your information will be securely stored for 7 years after the completion of the study at Dilico. Your consent form will be stored separately from any collected data (i.e., sharing circle or interview data). These files will be stored in a locked filing cabinet in a locked office at Dilico, like all other client files.

Registration information (e.g., contact information) will be stored on a password-protected, encrypted Microsoft Excel document. Only Brittany Skov and Alexa Curci will have access to this information. The document will be saved using secure cloud storage.

Sharing circle and interview data will be stored briefly on a handheld audio recorder, before being downloaded onto an encrypted and password protected cloud-based secure folder. Audio recordings will be transcribed into text. All identifying information will be removed. The audio recordings will then be destroyed. The text versions will be saved in an encrypted and password protected file, saved on a secure cloud-based server. Electronic versions of de-identified data will be held for an indefinite period and will be kept in a password-protected USB drive in Dr. Mushquash's locked laboratory for a brief time and then will be held for 7 years at Dilico.

Questionnaire data (e.g., age, sex, First Nations, Métis, and/or Inuit ancestry, income, nature of employment (e.g., full-time, part-time, etc.), history of brain health changes associated with older age, and brain health perspectives, will be used by researchers at Lakehead University for a brief time and then stored at Dilico. This data will not be connected to any specific information shared at sharing circles or interviews.

**Limits of Confidentiality**

We will keep your records private to the extent allowed by law. We will need to breach your confidentiality only if:

a) You tell us that you intend to harm yourself

b) You tell us that you intend to harm someone else

c) You inform us that a child is currently at risk for abuse or neglect

d) You report sexual abuse by a health care practitioner

e) You report that an older adult living in a long-term or residential care facility is being harmed

e) Your records are subject to a subpoena by the courts (records can be opened by a specific court order, but it is highly unlikely that this will happen)

f) *Or*, to the extent required by the law

**What will my data be used for?**

It is anticipated that the results of this study will be shared with others in the following ways: thesis and/or classroom presentations, presentations at academic meetings, published articles in peer-reviewed journals, and/or presentations within the community. The research findings may be used by Dilico Anishinabek Family Care to inform and support services. As part of such distribution, all information will remain confidential and personally identifying information will never be revealed. The research findings will not be commercialized.

**How can I receive a copy of the research results?**

You will have the opportunity to review and provide feedback on an initial summary of the study results. If you would like to do so, please indicate this on the study consent form and provide your contact information.

If you would like to receive a summary of the final study results, you can indicate this on the study consent form and provide your contact information.

Individual results will not be made available to participants.

**What if I want to withdraw from the study?**

After registering, you may withdraw from the study prior to the sharing circle or interview. Please contact Brittany Skov (surg@lakeheadu.ca) to officially withdraw.

During the sharing circle or interview, you will be permitted to leave without penalty. You may choose not to answer any of the questions.

Your data may be able to be removed from the study after the data collection. If you choose to attend an interview, you may withdraw your interview data up to 2 weeks after the interview without penalty. To do so, please contact Brittany Skov (surg@lakeheadu.ca). Due to the collaborative nature of sharing circles, it will not be possible to remove your data after data collection.

The research team reserves the right to end your participation for any reason.

**Researcher Contact Information**

Principal Investigator: Dr. Christopher Mushquash, Lakehead University, in collaboration with Dilico Anishinabek Family Care

Co-Investigator: Brittany Skov, Lakehead University

Email: bskov@lakeheadu.ca

**Research ethics board review and approval:**

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Lakehead University's Research Ethics Board for assistance at (807) 343-8283.

This study has been approved by the Lakehead University Research Ethics Board (1470750). If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

***Please retain a copy of this letter for your reference.***

**Consent Form**

**MY CONSENT:**

I agree to the following:

- ✓ I have read and understand the information contained in the Information Letter
- ✓ I agree to participate
- ✓ I understand the risks and benefits to the study
- ✓ That I am a volunteer for this study. I may withdraw from the study up to the start of the sharing circles, or remove my data up to 2-weeks after an interview. I understand that

data provided at sharing circles cannot be withdrawn. I may choose not to answer any question.

- ✓ That the data will be securely stored at Dilico Anishinabek Family Care for a minimum period of 7 years following completion of the research project
- ✓ I understand that the research findings will be made available to me upon request
- ✓ I will remain anonymous unless otherwise indicated (see below)
- ✓ All of my questions have been answered

By consenting to participate, I have not waived any rights to legal recourse in the event of research-related harm.

**Do you consent to having your interview audio recorded? Please note, sharing circles must be audio-recorded.**

- □ Yes
- □ No

**Would you like to use your actual name in published research results?**

- □ Yes, I consent to using my legal name in published research findings
- □ No, I would like to use a pseudonym in published research findings

If no, please provide a pseudonym: _____

**Do you consent to sharing a non-sensitive photo or object that is relevant to the study topic at the sharing circle or interview?**

- □ Yes, I consent
- □ No, I do not consent

**Do you consent to the research team and Dilico Anishinabek Family Care using your provided image or photo of your object when sharing research results? Examples may include published reports and videos.**

- □ Yes, I consent
- □ No, I do not consent

**For interviewees only: Would you like to receive a copy of your interview transcript, to have an opportunity to add, remove, or change your responses?**

- □ Yes
- □ No

**Would you like to be contacted to view and provide feedback on initial results prior to us finalizing them?**

- □ Yes
- □ No

If you would like to receive a copy of the results, please provide us with your contact information:

**Mailing Address** **Email Address**

_____

Name of Participant (please print)

_____ _____

Signature of Participant Date

**Appendix C: Email, Phone, and In-Person Recruitment Script (Dilico Healthcare Worker)**

Hello,

My name is [name]. I am a [health care professional] at Dilico Anishinabek Family Care.

I would like to invite you to the Anishinabek Brain Aging in Older Adults Study.

This research is being done as part of Brittany Skov's Master Project, a graduate student at Lakehead University. Her supervisor is Dr. Christopher Mushquash, a Professor at Lakehead University.

This project is co-led by Dilico Anishinabek Family care. Together, we are gathering the insights and perspectives of First Nations, Metis, and Inuit adults on brain aging symptoms, brain health promotion and assessment, and supporting older adults with changes in brain health (e.g., memory loss and thinking difficulties). We hope that this research helps to inform culturally safe brain aging care for First Nations, Métis, and Inuit adults in Northwestern Ontario.

To participate you need to be First Nations, Métis, or Inuit, 18+, live in the Thunder Bay district, and be able to read/speak English.

If you agree to volunteer you will be asked to attend either an in-person knowledge gathering circle, with up to 10 other people, or a one-on-one interview.

If you chose to attend a knowledge gathering circle, your participation will involve attending a 3 to 3.5 hour knowledge gathering circle, with a feast. You will be invited to share your perspectives and views on brain aging symptoms (e.g., memory loss), brain health promotion and assessment, and supporting older adults with changes in their brain health (e.g., memory loss). The knowledge gathering circle will be held by a local Elder or Knowledge Holder.

If you choose to attend an interview, your participation will involve attending a 1 to 1.5 hour interview. You will be invited to share your perspectives and views on brain aging symptoms (e.g., memory loss), brain health promotion and assessment, and supporting older adults with changes in their brain health (e.g., memory loss). You have the option of opting to have an Elder or Knowledge Holder attend.

During the knowledge gathering circle or interview, you will be invited to share an image (e.g., photograph, drawing, artwork) or meaningful object that depicts something that helps you age well in Northwestern Ontario. This is optional.

You will also complete a short questionnaire (15 minutes), including demographic information, perspectives on brain health.

In appreciation of your time, you will receive a $75 Mastercard Gift Card. A meal is included. For knowledge gathering circle participants, a feast will be offered after the knowledge gathering circle. For interviewees, an additional $30 gift card will be provided, in lieu of a meal.

Your participation is completely voluntary and if you choose not to participate it will not impact your relationship with Dilico Anishinabek Family Care or Lakehead University. Your decision to participate in the study will have no bearing on services that they are currently receiving or will receive in the future from Dilico Anishinabek Family Care.

Some individuals may receive assistance from a legal or substitute decision maker in making healthcare and other decisions. If a legal or substitute decision maker has been appointed, they must provide signed informed consent, either in advance by email or in person. The research team will also obtain the participant's permission or assent in person.

Care partners, including legal and substitute decision makers, are welcome to attend the knowledge gathering circle or interview to provide support. Care partners and decision makers attending the knowledge gathering circles or interviews who wish to participate are required to sign an informed consent letter and complete the questionnaire.

The research is funded by Mitacs, Heart & Stroke, Brain Canada, the Canadian Institutes for Health Research, and Psi Chi: The International Honor Society for Psychology.

This study has been reviewed and approved by the Research Ethics Board at Lakehead University and the Research Advisory Board at Dilico Anishinabek Family Care.

If you are interested in more information about the study or would like to volunteer, please email Brittany Skov at surg@lakeheadu.ca, or phone 905-988-3229 to register.

[Provide a flyer if in-person].

You may also contact Brittany Skov at surg@lakeheadu.ca with any questions.

Miigwech/Thank you,

Anishinabek Brain Aging in Older Adults Study

## Appendix D: Assent Script

Welcome to the Anishinabek Brain Aging in Older Adults Study!

I am a graduate student at Lakehead University, supervised by Dr. Christopher Mushquash. I have invited you to contribute to this study because you are a First Nations, Métis, or Inuit adult who has perspectives on brain aging among older adults (e.g., memory loss and thinking) that we'd like to learn more about. This information may help us better understand brain aging to promote brain health for older adults.

We have collaborated with Dilico Anishinabek Family Care. They are helping to lead the study and will have access to the findings and personal information. What you tell us will not be connected to your identity. It is important for you to know that your choice to participate in this study will not change the quality of care that you may receive.

I would like to invite you to be a part of this study today. Nobody will make you be a part of the study, and no one will be upset if you don't want to do it. If you decide to be a part of the study, but change your mind later, you can stop. It is your choice. I am now going to share some information about the study to help you decide. You can stop me at any time, request a break, or ask any questions.

**What will we ask you?**

In an interview/group format, we will ask you questions about brain aging symptoms, brain health promotion, assessing brain health, and caring for older adults who have changes in their brain health (e.g., memory loss). There will also be a short survey for personal information, like age, and brain aging questions. You can choose to skip any questions you do not wish to answer.

**What do I need to do?**

[For knowledge gathering circles] Your participation will include attending a knowledge gathering circle, with a feast. You will also complete a short survey. You will join a group of people, including a graduate student at Lakehead University and an Elder or Knowledge Holder. We will talk for about 3 hours.

**[If they brought a photo/object]**

[Care partner] and yourself brought an image or object that shows something that helps you age well in your community. You will be invited to tell the group about the image or object.

**[For interviews]**

We will talk for about 1.5 hours and you will also complete a short survey.

**[If they brought a photo/object]**

[Care partner] and yourself brought a photo or object that shows something that helps you age well in your community. You will be invited to tell me about the photo or object.

**[If the care partner is/not attending]**

[Care partner name] will be/will not be attending the knowledge gathering circle or interview. Are you O.K. with this?

**Can anything bad happen to you?**

**[knowledge gathering circle]**

You might feel embarrassed or uncomfortable when answering some of the questions or hearing other people sharing their perspectives. You will also be in the knowledge gathering circle for 3 hours, which may feel inconvenient. If you don't want to answer any of the questions, you don't

have to. Nobody will be upset with you. I will do everything we can do to make you feel comfortable. But if you do not feel good about anything you can stop anytime.

**[Interview]**

You might feel embarrassed or uncomfortable when answering some of the questions. We will also be talking for up to 1.5 hours, which may feel inconvenient. If you don't want to answer any of the questions, you don't have to. Nobody will be upset with you. I will do everything we can do to make you feel comfortable. But if you do not feel good about anything you can stop anytime.

**Will this study help you?**

Sometimes good things happen to people who are in a research study. I don't know if you will be helped by being in the study. But this study will help us learn more about something important. This will hopefully help other adults like you. This is a benefit.

To honor your contributions to this study, you will be eligible to receive a $75 Mastercard gift card. For participants attending a knowledge gathering circle, a meal is provided. For participants attending an interview, an additional $30 gift card will be provided, in lieu of a meal.

**Who will know that you are in this study?**

Only [care partner name], the research team, and some staff at Dilico Anishinabek Family Care will know that you are in this study. Your answers to the questions will have a code name so nobody will know what you personally shared.

We will share the results of the study with other people publicly. However, we will not share your name or any information that might reveal your identity.

There are some unlikely instances where I may have to share with others your identity and the information you share. For instance, if you tell me that you plan to hurt yourself or someone else, if a child is at-risk of harm, if you report sexual abuse by a health care provider, if you report that an older adult living in a long-term or residential care facility is being harmed, or as required by law.

**Do you have any questions?**

You can ask me, or [care partner] questions about the study at any time. There are no bad questions.

**Assent to participate**

Before you decide if you want to take part in this study, make sure you understand what you need to do and that all of your questions have been answered.

**Do you agree to take part in this study?**

- ☐ Yes
- ☐ No

**Do you consent to having your interview audio recorded? Please note, knowledge gathering circles must be audio-recorded.**

- ☐ Yes
- ☐ No

**Would you like to use your actual name in published research results?**

- ☐ Yes, I consent to using my legal name in published research findings

- ☐ No, I would like to use a pseudonym in published research findings If no, please provide a pseudonym:

**Do you consent to sharing a non-sensitive photo that is relevant to the study topic at the knowledge gathering circle or interview?**

- ☐ Yes, I consent
- ☐ No, I do not consent

**Do you consent to the research team and Dilico Anishinabek Family Care using your provided image when sharing research results? Examples may include published reports and videos.**

- ☐ Yes, I consent
- ☐ No, I do not consent

**For interviewees only: Would you like to receive a copy of your interview transcript, to have an opportunity to add, remove, or change your responses?**

- ☐ Yes
- ☐ No

**Would you like to be contacted to view and provide feedback on initial results prior to us finalizing them?**

- ☐ Yes
- ☐ No

Signature of the person obtaining assent

By signing this form, I attest that:

- I have explained the study to the prospective participant
- I answered all of their questions to the best of my ability
- I provided a copy of this assent form to the participant
- The participant seemed to understand the assent form and agreed to participate

_____

Name

_____

Signature

_____

Date

## Appendix E: Demographic Questionnaire

### Demographic Questionnaire

### Anishinabek Brain Aging in Older Adults Study

Your responses to this questionnaire are confidential. Please see the letter of information to learn about data storage and confidentiality.

This survey asks about dementia. Dementia is a health condition that affects memory, thinking, and understanding over time. It's more than just forgetting things; it changes how a person connects with their own mind, heart, spirit, and sometimes with the world around them. This can affect how they communicate, remember, and carry out daily activities.

This survey also asks about culturally appropriate and safe healthcare.

Culturally appropriate and safe recommendations and advice acknowledge and include an understanding of cultural differences (e.g. Indigenous perspectives of aging well), personal experiences, norms and power imbalances in the health care system to help make health-related advice easier and safer for Indigenous populations.

1. **Please tell us about your Indigenous ancestry (e.g., First Nations):**

   _____

   _____

   _____

2. **Please tell us about your home community (e.g., First Nations reserve):**

   _____

   _____

3. **What is your date of birth? (Month/Day/Year):**

_____

4. **What was your assigned sex at birth?:**

- Male
- Female
- Intersex
- Do not wish to disclose

5. **Please tell us about your gender identity (e.g., woman, man, Two-Spirit):**

_____

6. **Do you live in an urban, suburban or rural area?**

_____

7. **Do you live on-reserve?**

    - Yes
    - No
    - No response

8. **If you live on-reserve, which reserve do you live in?**

_____

9. **What is your approximate household annual income?**

_____

**10. How many people are supported by your household income, including yourself?**

_____

**11. Who do you currently live with? (e.g., alone, assisted living):**

_____

_____

**12. Do you provide care for an older adult or a person living with chronic illness? Please explain.**

_____

_____

_____

**13. What is your highest level of education?**

- Completed elementary school
- High school diploma or equivalent
- Some college/university
- College diploma
- University degree (Bachelor's)
- Graduate or professional degree (Master's, PhD, etc.)

**14. What is your current employment status (select all that apply)?**

- Employed full-time
- Employed part-time
- Self-employed
- Stay at home parent or grandparent
- Stay at home caregiver

- Unemployed, looking for work
- Unemployed, not looking for work
- Disability
- Retired
- Student
- Other: [_____]

**15. Do you know anyone who is living/has lived with dementia? (select all that apply)**

- My spouse/partner
- My parent(s)
- Extended family member(s)
- Friend(s), neighbour(s), or colleague(s) from work
- Community member(s)
- Elder(s) and/or Knowledge Keeper(s)
- Other (please specify) _____
- No one
- Don't know/No response

**Miigwech/Thank you for completing this survey. Please place your survey in the envelope provided and hand it to the research team.**

## Appendix F: Interview and Knowledge Gathering Circle Questions

### Interview Questions

1. Can you tell me a bit about yourself?

2. Tell me a story about a time, now or anytime in your life, when you thought an older adult might be having challenges with their memory or thinking.

Follow-up: How did they change (e.g., behaviors or mannerisms)

Follow-up: What do you think might have caused this?

3. Tell me about a time when an Elder or a Knowledge Holder talked about memory loss or forgetting.

Follow up: Are there any teachings or stories about memory loss or changes as we get older in your community?

Follow up: Do you know of any Anishinabemowin words that describe memory loss, or dementia?

4. Think about a time when someone in your community was experiencing memory loss. How did they find support?

Follow-up: How did the community respond?

Follow-up: How did family members respond?

5. Think about someone you know in your community living with memory loss. Tell us about how they continue to live well.

Follow-up: What are some barriers that they experience, or may experience, in living well?

6. Tell us the story of the image or object you brought to share today. How does this help you age well in your community?

7. Are there any other stories you'd like to share about what helps you age well in your community?

8. Is there anything else you'd like to share that I haven't asked about today?

9. How are you feeling about our gathering today? Are there ways that we could improve or things that we could do differently?

10. How would you like us to share the findings within the community?

**Knowledge Gathering Circle Questions**

1. Can you tell us a bit about yourself?

2. Tell me a story about a time, now or anytime in your life, when you thought an older adult might be having challenges with their memory or thinking.

Follow-up: How did they change (e.g., behaviors or mannerisms)

Follow-up: What do you think might have caused this?

3. Tell us about a time when Elders or Knowledge Holders talked about memory loss or forgetting.

Follow up: Are there any teachings or stories about memory loss or changes as we get older in your community?

Follow up: Do you know of any Anishinabemowin words that describe memory loss, or dementia?

4. Think about a time when someone in your community was experiencing memory loss. How did they find support?

Follow-up: How did the community respond?

Follow-up: How did family members respond?

5. Think about someone you know in your community who is living with memory loss. Tell us about how they continue to live well.

Follow-up: What are some barriers that they experience, or may experience, in living well?

6. Tell us the story of the image or object you brought to share today. How does this help you age well in your community?

7. Does anyone have any thoughts on [name]'s image/object?

8. Are there any other stories you'd like to share about what helps you age well in your community?

9. Is there anything else you'd like to share that I haven't asked about today?

10. How are you feeling about our gathering today? Are there ways that we could improve or things that we could do differently?

11. How would you like us to share the findings within the community?

## Appendix G: Group Consent and Knowledge Gathering Circle Script

## Anishinabek Brain Aging in Older Adults Study

Thank you for meeting with me today.

My name is Brittany Skov, and I am a Mississauga Nishnaabkwe and member of the Mississauga's of the Credit First Nation. I am also a graduate student at Lakehead University, in the clinical psychology program, supervised by Dr. Christopher Mushquash. I am also a daughter, older and younger sister, friend, and dog-mom. I am fortunate to call Thunder Bay home, but have also lived in many places, like St. Catharines, Banff, Lake Louise, Victoria, Dryden, and Prince George.

The number of First Nations, Métis, and Inuit older adults living with brain health difficulties (e.g., unexpected, age-related, progressive, and irreversible cognitive decline, such as memory loss) is increasing in Canada. Sometimes, these symptoms are common experiences related to aging, but sometimes these symptoms can be part of a disease that is diagnosed as dementia by a physician.

Healthcare organizations and governments need to make sure that brain health efforts, including prevention, assessment, and post-diagnosis care when someone has a disease, respect the unique needs of First Nations, Métis, and Inuit peoples.

Understanding brain health perspectives and support systems among First Nations, Métis, and Inuit peoples in Northwestern Ontario may help Dilico Anishinabek Family Care better support older adults at risk for, or living with, changes to brain health (e.g., memory loss).

As part of my Master's degree at Lakehead University, I am running a research study to examine brain aging perspectives among First Nations, Métis, and Inuit peoples, including the cultural

meaning of dementia symptoms, and approaches to prevention, assessment, and post-diagnosis care, and existing strengths (e.g., individual, interpersonal, and community strengths) that could promote brain aging in Northwestern Ontario.

Taking part in this study is voluntary. Before we get started, we will review the informed consent form together.

This project is partnered with Dilico Anishinabek Family Care, who provides leadership on the project development and management. Dilico Anishinabek Family Care will have ownership and access to the data, including personal information. Personal information will not be directly connected to the information you share. You are free to refuse to participate or to withdraw from the study at any time without changing in any way the quality of care that you receive.

This study is funded by Mitacs, Mental Health Research Canada, the Heart & Stroke Foundation, Brain Canada, the Canadian Institute of Health Research, and Psi Chi: The International Honor Society of Psychology.

You are being asked to participate in this study because you are a First Nations, Métis, or Inuit adult, aged 18+, with an interest in, living experience of, or experience supporting others with changes to brain health in older age (e.g., unexpected age-related, progressive, and irreversible cognitive decline, such as memory loss).

If you consent to voluntarily participate in this research, you will be invited to share your stories, perspectives, and experiences with brain health changes in older age (e.g., memory loss), brain health promotion, assessment, and post-diagnosis care, and existing strengths in the community that support brain health care for older adults. If you brought an image or object today, you will

be invited to share it with me. You will also be asked a short series of demographic and brain aging questions. You can choose to skip any questions you do not wish to answer.

We will be meeting today for about 3 hours to 3.5 hours.

I value and respect your rights as a knowledge contributor/participant in this study. You are under no obligation to participate in this study. You are free to withdraw at any time without prejudice to pre-existing entitlements and services provided by Dilico Anishinabek Family Care. You will be given, in a timely manner throughout the course of the research project, information that is relevant to your decision to continue or withdraw from participating.

There is a possibility that answering some of the questions may make you feel upset. If you feel upset at any time during the knowledge gathering circle, you may exit the circle. There is contact information on the letter of information if you require additional support.

There are minimal individual benefits to participating in this study. You may find it satisfying to contribute to research programs and/or contribute to our understanding of brain health perspectives and support systems among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

To honor your contributions to this study, you will receive a $75 Mastercard gift card. A feast will also be provided after the knowledge gathering circle.

To ensure anonymity, Your individual information will not appear in any reports or publications. All information will only be used when it is combined with other participants' information, without your name or other information that would identify you.

Some folks may wish to include their name in published research reports, whereas others may wish to use a fake name (i.e., a pseudonym).

Several steps have also been taken to protect your confidentiality. All information obtained is strictly confidential. The information you provide will only be accessed by designated members of the research team. All Dilico staff are trained to maintain your confidentiality and have signed confidentiality agreements.

Due to the nature of knowledge gathering circles (e.g., group format), we are unable to guarantee confidentiality. However, the research team will remind and invite participants to respect each other's privacy.

Consistent with Lakehead University's policy on research data storage, paper copies of your information will be securely stored for 7 years after the completion of the study at Dilico. Your consent form will be stored separately from any collected data (i.e., knowledge gathering circle or interview data). These files will be stored in a locked filing cabinet in a locked office at Dilico, like all other client files.

Registration information (e.g., contact information) will be stored on a password-protected, encrypted Microsoft Excel document. Only myself and a research assistant, Alexa Curci, will have access to this information. The document will be saved using secure cloud storage.

knowledge-gathering circle data will be stored briefly on a handheld audio recorder, before being downloaded onto an encrypted and password protected cloud-based secure folder. Audio recordings will be transcribed into text. All identifying information will be removed. The audio recordings will then be destroyed. The text versions will be saved in an encrypted and password protected file, saved on a secure cloud-based server. Electronic versions of de-identified data will

be held for an indefinite period and will be kept in a password-protected USB drive in Dr. Mushquash's locked laboratory for a brief time and then will be held for 7 years at Dilico.

Survey data will be used by researchers at Lakehead University for a brief time and then stored at Dilico. This data will not be connected to any specific information shared at knowledge-gathering circles or interviews.

It is anticipated that the results of this study will be shared with others in the following ways: thesis and/or classroom presentations, presentations at academic meetings, published articles in peer-reviewed journals, and/or presentations within the community. The research findings may be used by Dilico Anishinabek Family Care to inform and support services. As part of such distribution, all information will remain confidential and personally identifying information will never be revealed. The research findings will not be commercialized.

You will have the opportunity to review and provide feedback on an initial summary of the study results. I have noted your preference.

If you would like to receive a summary of the final study results, you can indicate this on the study consent form and provide your contact information. I have noted your preference.

Individual results will not be made available to participants.

Due to the collaborative nature of the knowledge-gathering circle, you do not have the option of removing your data after the knowledge-gathering circle is completed.

We will keep your records private to the extent allowed by law. We will need to breach your confidentiality only if:

a) You tell us that you intend to harm yourself

b) You tell us that you intend to harm someone else

c) You inform us that a child is currently at risk for abuse or neglect

d) You report sexual abuse by a health care practitioner

e) You report that an older adult living in a long-term or residential care facility is being harmed

e) Your records are subject to a subpoena by the courts (records can be opened by a specific court order, but it is highly unlikely that this will happen)

f) Or, to the extent required by the law

If you have chosen to provide written consent, please complete the informed consent letter if you have not yet already.

Has anyone in the group chosen to provide verbal/oral consent?

**Oral Consent Script**

If the participant has opted for oral consent, include the following and note in the oral consent log.

Do you agree to participate in this study?

If yes,

- Do you consent to having the knowledge-gathering circle audio recorded?
- What name would you like us to use in published and public research documents?
- Do you consent to knowledge-gathering a non-sensitive photo that is relevant to the study topic at the knowledge-gathering circle?

- Do you consent to the research team and Dilico Anishinabek Family Care using your provided image when knowledge-gathering research results? Examples may include published reports and videos.
- Would you like to be contacted to view and provide feedback on the initial results prior to finalizing them? If yes, where should we send them (email, mailing address)?
- Would you like a copy of the final study results? If yes, where should we send them (email, mailing address)?

If no, "Thank you for your time."

Thank you for listening. We can now join together in the circle.

Elder: Opening prayer and smudge [no script provided].

Elder: Introduce cultural knowledge-gathering circle protocols [no script provided].

Thank you, X, for opening the circle in a good way.

**Circle Questions**

1. Can you tell us a bit about yourself?
2. Tell us a story about a time when you thought an older adult might be having challenges with their memory or thinking.
    a. Follow-up: How did they change mentally, physically, emotionally, spiritually?
    b. Follow-up: What do you think might have caused this?
3. Tell us about a time when Elders talked about memory loss or forgetting.
    a. Follow up: Are there any teachings or stories about memory loss or changes as we get older in your community?

   b. Do you know of any Anishinabowen words that describe memory loss, or dementia?

4. Think about a time when someone in your community was experiencing memory loss. How did they find support?
   a. Follow-up: How did the community respond?
   b. Follow-up: How did family members respond?
5. Think about someone you know in your community who is living with memory loss. Tell us about how they continue to live well, spiritually, emotionally, mentally, and physically.
6. Tell us the story of the image or object you brought to share today. How does this help you age well in Northwestern Ontario? (spiritually, mentally, physically, emotionally).
7. Does anyone have any thoughts on [name]'s image/object?
8. Is there anything else you'd like to share that I haven't asked about today?
9. How are you feeling about our gathering today? Are there ways that we could improve?
10. How would you like us to share the findings within the community?

Thank you to everyone for sharing your insights. I feel deeply grateful to have been able to learn with you today.

**Debriefing**

The purpose of this study was for us to better understand community member's perspectives and views on brain aging.

Some studies have suggested that the way people understand a health condition can impact care preferences and behaviors. When older adults become more forgetful or have troubles with their

thinking, a healthcare provider may consider a diagnosis of dementia, such as Alzheimer's dementia. Alzheimer's disease causes Alzheimer's dementia.

Research has shown that in some First Nations communities, brain health changes among older adults, such as memory loss, are not understood as resulting from a disease, such as Alzheimer's disease. We wanted to learn about the meaning of brain health symptoms among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

Different communities also have different approaches to promoting brain health among older adults, such as connecting to the land. We wanted to learn about approaches to promoting brain health as people age among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

Typically, when an older adult is experiencing changes to their brain health, such as memory loss, a healthcare professional conducts a series of medical assessments, such as memory tests. The results of these tests help healthcare professionals, family members, and others, better support the older adult. Research with some Indigenous communities have suggested that there are other symptoms that would be indicative that an older adult might benefit from additional support due to changes in their brain health.

Communities also have different approaches to supporting other adults who are experiencing changes to their brain health, such as memory loss. We wanted to understand how best to support older adults in Northwestern Ontario with changes to their brain health.

We also wanted to learn about resources and strengths inherent in individuals, families, and communities that support brain aging in Northwestern Ontario.

If you experienced any distress during the study, you may want to talk to a professional about wholistic wellness. We have provided a handout of wholistic wellness resources, which will be available at the exit.

You may also contact

Dilico Anishinabek Family Care Health and Wellness Centre

17 Court Street South

Thunder Bay, ON, P7B 0E8

Phone: (807) 626-5100

Fax: (807) 626-7999

Toll-Free Fax: 1-855-626-7999

https://www.dilico.com/

Your participation will remain completely confidential. We will use the data you provided to analyze brain health, promotion, assessment, and post-diagnosis care for older adults, and existing strengths and resources in the community that promote brain health for older adults.

If you have any questions or concerns about your participation or this study, feel free to contact us at any time.

Thank you again for knowledge-gathering and learning with us today.

We will now gather for a feast. We will have a closing ceremony in 40 minutes.

Feast.

[Closing ceremony conducted by Elder].

## Appendix H: Interview Script

## Anishinabek Brain Aging in Older Adults Study

Thank you for meeting with me today.

My name is Brittany Skov, and I am a Mississauga Nishnaabkwe and member of the Mississauga's of the Credit First Nation. I am also a graduate student at Lakehead University, in the clinical psychology program, supervised by Dr. Christopher Mushquash. I am also a daughter, older and younger sister, friend, and dog-mom. I am fortunate to call Thunder Bay home, but have also lived in many places, like St. Catharines, Banff, Lake Louise, Victoria, Dryden, and Prince George. Alexa Curci is a research assistant on this study.

As part of my Master's degree at Lakehead University, I am conducting a research study to examine brain aging perspectives among First Nations, Métis, and Inuit peoples, including the cultural meaning of dementia symptoms, and approaches to prevention, assessment, and post-diagnosis care, and existing strengths (e.g., individual, interpersonal, and community strengths) that could promote brain aging in Northwestern Ontario.

I estimate that the interview will take about 1 hour, and there will be 10 questions. You are welcome to not answer a question or change the question. If you do not want to answer a question, you can just say 'pass'. If you would like to skip the question and return to it later, we can also do that. There are no right or wrong answers to the questions. At the end, if there is anything else you would like to add, please do. If you have any questions, you can stop me at any time, and we can take a break if needed.

I would like to record the meeting today. The audio recording will be stored on an external drive until the interview is transcribed. During transcription, all identifying information is removed. After it is transcribed, the recording will be permanently deleted.

I will send you a copy of the transcript once it has been transcribed. At that time, if there is anything on the transcript that you want left out, or if there is something you want to add that you thought about later, please let me know.

Later in April/May, I will be analyzing the data from all of the interviews, to look for common themes. I can send you a copy of my analysis. If you feel like I have misinterpreted or misunderstood anything, please let me know and I can adjust.

You might also not wish to receive the transcript and/or analysis, which is also okay.

Before we get started, we will review the informed consent form together.

This project is partnered with Dilico Anishinabek Family Care, who provides leadership on the project development and management. Dilico Anishinabek Family Care will have ownership and access to the data, including personal information. Personal information will not be directly connected to the information you share. You are free to refuse to participate or to withdraw from the study at any time without changing in any way the quality of care that you receive.

This study is funded by Mitacs, Mental Health Research Canada, the Heart & Stroke Foundation, Brain Canada, the Canadian Institute of Health Research, and Psi Chi: The International Honor Society of Psychology.

You are being asked to participate in this study because you are a First Nations, Métis, or Inuit adult, aged 18+, with an interest in, living experience of, or experience supporting others with

changes to brain health in older age (e.g., unexpected age-related, progressive, and irreversible cognitive decline, such as memory loss).

You will be invited to share your stories, perspectives, and experiences with brain health changes in older age (e.g., memory loss), brain health promotion, assessment, and post-diagnosis care, and existing strengths in the community that support brain health care for older adults. If you brought an image or object today, you will be invited to share it with me. You will also be asked a short series of demographic and brain aging questions. You can choose to skip any questions you do not wish to answer.

We will be meeting today for about 1 hour to 1.5 hours.

I value and respect your rights as a knowledge contributor/participant in this study. You are under no obligation to participate in this study. You are free to withdraw at any time without prejudice to pre-existing entitlements and services provided by Dilico Anishinabek Family Care. You will be given, in a timely manner throughout the course of the research project, information that is relevant to your decision to continue or withdraw from participating.

There is a possibility that answering some of the questions may make you feel upset. If you feel upset at any time during the interview, we can stop. There is contact information on the letter of information if you require additional support.

There are minimal individual benefits to participating in this study. You may find it satisfying to contribute to research programs and/or contribute to our understanding of brain health perspectives and support systems among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

To honor your contributions to this study, you will receive a $75 Mastercard gift card. I will also provide you with an additional $30 gift card, in lieu of a meal. This will be provided to you at the end of the interview.

To ensure anonymity, your individual information will not appear in any reports or publications. All information will only be used when it is combined with other participants' information, without your name or other information that would identify you.

Some folks may wish to include their name in published research reports, whereas others may wish to use a fake name (i.e., a pseudonym). I have noted your preference from your form.

Several steps have also been taken to protect your confidentiality. All information obtained is strictly confidential. The information you provide will only be accessed by designated members of the research team. All Dilico staff are trained to maintain your confidentiality and have signed confidentiality agreements.

Consistent with Lakehead University's policy on research data storage, paper copies of your information will be securely stored for 7 years after the completion of the study at Dilico. Your consent form will be stored separately from any collected data (i.e., sharing circle or interview data). These files will be stored in a locked filing cabinet in a locked office at Dilico, like all other client files.

Registration information (e.g., contact information) will be stored on a password-protected, encrypted Microsoft Excel document. Only Brittany Skov and Alexa Curci will have access to this information. The document will be saved using secure cloud storage.

Sharing circle and interview data will be stored briefly on a handheld audio recorder, before being downloaded onto an encrypted and password protected cloud-based secure folder. Audio

recordings will be transcribed into text. All identifying information will be removed. The audio recordings will then be destroyed. The text versions will be saved in an encrypted and password protected file, saved on a secure cloud-based server. Electronic versions of de-identified data will be held for an indefinite period and will be kept in a password-protected USB drive in Dr. Mushquash's locked laboratory for a brief time and then will be held for 7 years at Dilico.

The survey will be used by researchers at Lakehead University for a brief time and then stored at Dilico. This data will not be connected to any specific information shared at sharing circles or interviews.

It is anticipated that the results of this study will be shared with others in the following ways: thesis and/or classroom presentations, presentations at academic meetings, published articles in peer-reviewed journals, and/or presentations within the community. The research findings may be used by Dilico Anishinabek Family Care to inform and support services. As part of such distribution, all information will remain confidential and personally identifying information will never be revealed. The research findings will not be commercialized.

You will have the opportunity to review and provide feedback on an initial summary of the study results. I have noted your preference.

If you would like to receive a summary of the final study results, you can indicate this on the study consent form and provide your contact information. I have noted your preference.

Individual results will not be made available to participants.

You may withdraw your interview data up to 2 weeks after the interview without penalty. To do so, please contact me at (bskov@lakeheadu.ca).

We will keep your records private to the extent allowed by law. We will need to breach your confidentiality only if:

a) You tell us that you intend to harm yourself

b) You tell us that you intend to harm someone else

c) You inform us that a child is currently at risk for abuse or neglect

d) You report sexual abuse by a health care practitioner

e) You report that an older adult living in a long-term or residential care facility is being harmed

e) Your records are subject to a subpoena by the courts (records can be opened by a specific court order, but it is highly unlikely that this will happen)

f) Or, to the extent required by the law

**Oral Consent Script**

If the participant has opted for oral consent, include the following and note in the oral consent log.

Do you agree to participate in this study?

If yes,

- Do you consent to having your interview audio recorded?
- Would you like to receive a copy of your interview transcript, to potentially make changes?
- What name would you like us to use in published and public research documents?
- Do you consent to sharing a non-sensitive photo that is relevant to the study topic at the sharing circle [or interview]?

- Do you consent to the research team and Dilico Anishinabek Family Care using your provided image when sharing research results? Examples may include published reports and videos.
- Would you like to be contacted to view and provide feedback on the initial results prior to finalizing them? If yes, where should we send them (email, mailing address)?
- Would you like a copy of the final study results? If yes, where should we send them (email, mailing address)?

If no, "Thank you for your time."

Elder [if requested]: Opening prayer and smudge [no script provided].

Are there any questions before we begin?

**Demographic Questionnaire and Brain Health Survey**

Let's first complete the demographic questionnaire and brain health survey. Would you like to complete this on your own, or with me?

**Interview questions**

**1. Can you tell me a bit about yourself? (e.g., where you are from, demographics, interests)**

**2. Tell me a story about a time, now or anytime in your life, when you thought an older adult might be having challenges with their memory or thinking.**

*Follow-up: How did they change (e.g., behaviors or mannerisms)*

*Follow-up: What do you think might have caused this?*

**3. Tell me about a time when Elders or Knowledge Holder talked about memory loss or forgetting.**

*Follow up: Are there any teachings or stories about memory loss or changes as we get older in your community?*

*Follow up :Do you know of any Anishinabemowin words that describe memory loss, or dementia?*

**4. Think about a time when someone in your community was experiencing memory loss. How did they find support?**

*Follow-up: How did the community respond? Follow-up: How did family members respond?*

*Probe: Do you remember any stories or memories of what you've just described?*

*Probe: What happened next?*

**5. Think about someone you know in your community living with memory loss. Tell us about how they continue to live well.**

*Follow-up: What are some barriers that they experience, or may experience, in living well?*

*Probe: Do you remember any stories or memories of what you've just described?*

*Probe: What happened next?*

**6. Tell us the story of the image or object you brought to share today. How does this help you age well in your community?**

*Probe: Do you remember any stories or memories of what you've just described?*

*Probe: What happened next?*

**7. Are there any other stories you'd like to share about what helps you age well in your community?**

*Probe: Do you remember any stories or memories of what you've just described?*

*Probe: What happened next?*

**8. Is there anything else you'd like to share that I haven't asked about today?**

**9. How are you feeling about our gathering today? Are there ways that we could improve or things that we could do differently?**

**10. How would you like us to share the findings within the community?**

**Debriefing** Thank you to everyone for sharing your insights. I feel deeply grateful to have been able to learn with you today.

The purpose of this study was for us to better understand community member's perspectives and views on brain aging.

Some studies have suggested that the way people understand a health condition can impact care preferences and behaviors. When older adults become more forgetful or have troubles with their thinking, a healthcare provider may consider a diagnosis of dementia, such as Alzheimer's dementia. Alzheimer's disease causes Alzheimer's dementia.

Research has shown that in some First Nations communities, brain health changes among older adults, such as memory loss, are not understood as resulting from a disease, such as Alzheimer's disease. We wanted to learn about the meaning of brain health symptoms among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

Different communities also have different approaches to promoting brain health among older adults, such as connecting to the land. We wanted to learn about approaches to promoting brain health as people age among First Nations, Métis, and Inuit peoples in Northwestern Ontario.

Typically, when an older adult is experiencing changes to their brain health, such as memory loss, a healthcare professional conducts a series of medical assessments, such as memory tests. The results of these tests help healthcare professionals, family members, and others, better

support the older adult. Research with some Indigenous communities have suggested that there are other symptoms that would be indicative that an older adult might benefit from additional support due to changes in their brain health.

Communities also have different approaches to supporting other adults who are experiencing changes to their brain health, such as memory loss. We wanted to understand how best to support older adults in Northwestern Ontario with changes to their brain health.

We also wanted to learn about resources and strengths inherent in individuals, families, and communities that support brain aging in Northwestern Ontario.

If you experienced any distress during the study, you may want to talk to a professional about wholistic wellness. We have provided a handout of wholistic wellness resources, which will be available at the exit.

You may also contact

Dilico Anishinabek Family Care Health and Wellness Centre

17 Court Street South

Thunder Bay, ON, P7B 0E8

Phone: (807) 626-5100

Fax: (807) 626-7999

Toll-Free Fax: 1-855-626-7999

https://www.dilico.com/

Your participation will remain completely confidential. We will use the data you provided to analyze brain health, promotion, assessment, and post-diagnosis care for older adults, and existing strengths and resources in the community that promote brain health for older adults.

If you have any questions or concerns about your participation or this study, feel free to contact me at any time.

Thank you again for meeting with me today. Here is your gift card and meal card.

## Appendix I: Photovoice Images

**Figure 1**

*Infographic of photovoice photos and several supporting codes*