

**Indigenous Research Methodology in Action: The Development of a Functional
Assessment Tool for Dementia**

by

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Abstract

Dementia rates are rising significantly among Indigenous populations in Canada. The criteria for dementia diagnosis include assessing cognitive impairment and its impact on conducting everyday activities. Among everyday activities, the Instrumental Activities of Daily Living (IADLs) decline in the early stage of dementia. It includes cognitively complex activities such as grocery shopping, managing personal finances, cooking, laundry, etc. The existing IADL assessment tools are mainly developed and validated for the English-speaking White population and may be culturally inappropriate for use in an Indigenous context. Thus, to address this, I aimed: (1) to identify methods and approaches used in adapting and developing health assessment tools used for Indigenous populations across Canada, USA, Australia and Aotearoa/New Zealand, and (2) to conduct preliminary community-based research to inform the development of an Indigenous Functional Assessment tool.

The first phase of the study consisted of a scoping review. Five databases and three grey literature engines were searched from January 1st, 2000, to October 31st, 2021. An Indigenous Wholistic Framework was used to map the evidence. The second phase of the study was conducted in partnership with Maamwesying North Shore Community Health Services. The two focus groups were conducted with Indigenous and non-Indigenous health professionals assessing cognitive and functional decline in the Indigenous communities. The aim was to understand their experiences and perspectives and explore domains for a culturally relevant and appropriate functional assessment tool. A Community Advisory

Group, including an Elder, was formed to guide the research process. Thematic analysis was used to analyze the qualitative data.

The review identified the increasing use of Indigenous approaches in adapting and developing health assessment tools. Most of the tools were adapted and developed using the concepts of respect, relevance, responsibility, and reciprocity. The thematic analysis in the second phase identified six themes and eleven sub-themes. These themes included Indigenous understanding of dementia, late diagnosis and disease progression, challenges faced by health professionals, barriers to accessing health services, approaches to potential Functional Assessment tools and domains of a new tool.

The scoping review provided evidence of evolving standard approaches and methods while adapting and developing health assessment tools in Indigenous contexts. Furthermore, the community-based study was the first to understand the health professionals' perspectives regarding culturally appropriate functional assessment tools. It will lead a path for Maamwesying to prepare for research and development of functional assessment tool.

Keywords: Dementia, Indigenous Population, Functional Assessment, Instrumental Activities of Daily Living, Community-Based Participatory Research, Indigenous Research Paradigm, Scoping review, Focus Groups, First Nations, Decolonization, Relational Approach, Standardization

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Chapter 1

1. Introduction, Background and Research Objectives

1.1 Situating Self

While conducting Indigenous research, it is crucial for a researcher to situate themselves and describe how their position impacts the research process (Drawson et al., 2017). In this project, I, too, position myself for who I am as an individual, the context within which I have lived, and my relationship with the Indigenous community organization with whom I worked. These factors can potentially influence the research process and the research outcomes (Holmes, 2020). I have consistently self-reflected on my position and on the aspects of my identity shaped by racial background, personal beliefs, gender, cultural background, and my position as a researcher within the context of this study. I recognize that my experiences, perspectives, and viewpoints are unique and different from the community's. I constantly remind myself that these differences exist and are the foundation for developing respectful relationships with community members. In this section, I will position myself in terms of my cultural background and academic training, and my work towards laying a foundation for developing a functional assessment with First Nations communities to broadly improve the diagnosis of dementia in the communities.

1.1.1 My Early Family Life Experience

I was born and raised in Kathmandu, the capital city of Nepal. Nepal is a small landlocked country situated between India and China. Nepal is mostly known for its

landscape, especially Mount Everest and eight of the world's highest mountains. It is the birthplace of Buddha and home to over 30 million people of 125 caste/ethnic groups speaking 123 languages. Approximately, 40% of the total population belongs to Indigenous ethnic groups, while the remaining 60% belong to the Hindu varna system¹. Within these groups, the Government of Nepal has identified 59 groups as Indigenous nationalities called Adibasi/Janjati. In Nepal, the Indigenous nationality refers to “a tribe or community that have their own mother tongue and traditional customs, distinct cultural identity, distinct social structure and written or oral history of their own” (NFDIN, 2003). The Indigenous people do not fall under the conventional fourfold Varna of Hindu hierarchical caste structure (Mabuhang, 2014).

I belong to the Hindu varna system; thus, I am not an Indigenous person and acknowledge the privilege associated with this designation. I come from a middle-class family and am the eldest of three siblings- a brother and a sister, and the first child of my parents. I grew up in a traditional extended family of 20 people among my grandparents, parents, uncle, aunt and ten cousins. My family's income was from local business and agriculture. My father and uncle owned a grocery store and rice mills, while my mom and aunt were housewives. I grew up in the suburbs of Kathmandu, so I have both the experiences of rural and urban life. My grandfather never went to school to self-study and gained employment in the government's road department. Later in his life, he was into

¹ Hindu Varna system refers to a social class within a hierarchical case system in the context of Hinduism. Four varnas are ranked based on the occupations, requirements and duties that includes: Brahmin- scholar, priests or teachers; Kshatriya- ruler, administrator, or warriors; Vaishyas- agriculturalists, farmers or merchants and Shudras- Artisans, laborers or servants.

spiritual practices. I remember my grandmother as a fearless, strong lady; she is my role model. My father could not complete high school as he was involved in the family business. Throughout my upbringing, my family always stressed the importance of education. This inspired me to pursue a Ph.D. I still recall my grandmother's final words for me to focus on my studies.

My home was on the outskirts of the village, isolated from neighbours, but a family of 20 with 11 children was enough for us to engage with each other. We had a big farm around our house with many fruits and vegetables. After school, we watered those vegetables and fruits, while the labourers cultivated the rice, wheat, corn and potato. Although most of the farm has been occupied with buildings for the past three decades, I still, sometimes in my dreams, remember those days, roaming through fields plucking fruits and vegetables. We used to sleep with our grandmom, sharing the upper floor.

During festivals and winter vacations, we visited our maternal grandparents' house in a different city with a bus ride of 3-4 hrs. That was our exposure to the outer world. I still vividly recall my grandmother preparing tea, boiling milk and cooking meals in the mud kitchen early in the morning. My grandparents had a backyard with orange trees, and my grandmother hid the sweetest orange for us on her secret shelves. My siblings, cousins, and I used to climb these trees. My paternal and maternal grandparents used to tell us moral stories from the epics like Mahabharat, Ramayan and Bhagavad Gita with each carrying valuable lessons. My grandmother was a kind and generous lady who always supported and helped individuals within our community, especially young mothers, with food, clothing and financial assistance to access health care for their children. I recall my grandfather feeding

beggars, saints and animals before taking his meal. He had a profound love for animals, and as children, we had three cows and several dogs. Visitors from distant relations frequently visited our home during my grandparents' lifetime. This familial and cultural premise shaped my early years, emphasizing the importance of relationships with the land, people, animals, cosmos, and ideas.

1.1.2 My Educational Experience

I commenced my educational journey by pursuing a bachelor's degree in public health in Nepal. During my second year, we had a one-month-long community assessment program as a requirement of the degree. My classmates and I were sent to a remote rural village in the west of Nepal for a month. It was my first trip outside Kathmandu for a month without my family. We were sent to a village named Ghandruk, situated at an elevation of 2000 meters above sea level and inaccessible by road and vehicles. We had to transport our monthly food supplies, bedding, kerosene for stoves and toiletries by donkeys, requiring us to trek to the village. I led a team of nine classmates and was responsible for conducting household surveys, collecting demographic, health and environmental data and analyzing the information. Based on the findings, we were to identify the community's real needs and design and implement a small-scale project to address these needs. One of our mentors accompanied us to the village. Still, we were to find accommodation for a month, establish rapport with community members, government officials, and community leaders, conduct house-to-house surveys in a remote setting, and execute the community project. I still recall travelling the hilly terrain through rivers and forests, visiting homes, engaging with locals,

listening to their stories, and eating the offered food. The respect and humility that community members showed remain ingrained in my consciousness. I still hold dear to one of many beautiful and transformative experiences where a generous family offered us their children's beds on a rainy night. Such acts of compassion, humility and genuineness of the community people inspired me to do community-based work.

During my third year at university, I had experiences that continued to shape my perspectives on community health and human resilience. As per the degree requirement, we were sent to another district to learn about the district health system. During this time, an outbreak of food poisoning occurred in a remote village. One of our supervisors sent us to the affected village to collect data. Growing up in a semi-urban area, it was my second trip to a remote rural village. We got into a bus filled with sacks of rice, kerosene, and other grocery stuffs and sat over the sacks instead of a seat on a thin, narrow stretch of dusty, bumpy road. I vividly remember interviewing a family that tragically lost their mother to food poisoning, leaving behind an infant. This experience taught me a profound lesson in empathy, adaptability and the unpredictable nature of life.

After completing my undergraduate degree, I started my career as an advocate for Adolescent Sexual and Reproductive Health Rights. I joined a youth organization as an executive member. Further, I facilitated workshops for youths on HIV and AIDS, worked closely with LGBTQ communities, participated in youth sessions focused on LGBTQ+ advocacy in France, and chaired youth sessions at the International Conference on HIV and AIDS held in Bali. This exposure significantly contributed to my professional development, while empowering me to stand up and voice for the issues impacting the health and well-

being of the community people. Growing up in a closed community, my few years of exposure to the outer world led me towards my journey as a researcher. These experiences helped me to realize the value of advocacy, navigate a professional environment, actively listen to people's stories and develop global perspectives. Back home, I evaluated projects on uterine prolapse in rural communities, coordinated initiatives addressing food insecurity and climate change and championed consumer rights. I can proudly say that during my professional career, I was committed to building meaningful relationships with the communities I served.

While working full-time, I pursued a Master's degree in Anthropology. This was the time when I studied Western worldviews and theories and human evolution from Western perspectives. I will discuss how education influenced my worldview in the third chapter. Simultaneously, I joined a Master's program in Public Health at a reputed institution in Nepal. The program allowed me to engage and network with prominent and dedicated public health professionals. My passion and appreciation for the public health field and community-focused work resulted from the exposure and engagement I had during the formative years of my career. My MPH thesis centred on investigating health-seeking behaviours within urban slum populations, while my MA thesis examined tobacco consumption among carpet factory workers in Kathmandu.

I immigrated to Canada in 2016 and enrolled in the Interdisciplinary Rural and Northern Health Ph.D. Program in 2018. Before migrating to Canada, my knowledge of Canada's history of colonization and Indigenous people was limited. Individuals like me from the developing world often idealize the Western world as a place of equality and justice.

After having the opportunity to work with my current supervisor in 2016, I started to learn about Indigenous people's history and disparities in health. My long-standing aspiration to pursue a Ph.D. materialized after I shared it with my supervisor.

1.1.3 Positioning Myself within this Ph.D. Project

I worked on several public health issues back in Nepal, such as the issues of adolescents' sexual and reproductive health, HIV and AIDS, uterine prolapse, food security, and climate change, as these were pertinent at the time. However, I observed the shifting demographics of Nepal towards an aging population. I realized there was a lack of studies and interventions on the issues of aging populations. Upon arriving in Canada, I made an intentional shift in my career focus toward aging-related issues. I started working as a research assistant under the guidance of my current supervisor, Dr. Jennifer Walker. That project explored the differences in dementia diagnosis between Ontario and Saskatchewan. In the meantime, Dr. Walker was validating the *Canadian Indigenous Cognitive Assessment (CICA)*. I recognized the need for a culturally appropriate cognitive assessment tool in Nepal, where dementia was still a relatively new concept. Thus, I proposed adapting the original *Kimberley Indigenous Cognitive Assessment (KICA)* tool in the context of Nepal. As with the context of Indigenous populations in Canada, a validated tool for the Nepalese population was needed due to the language, education and cultural bias of the other mainstream dementia assessment tools.

My personal experience further underlines the relevance of my work. Back home, my mother-in-law suffered a stroke, and I had to return to Nepal. I stayed there for a year as a

caregiver and witnessed the profound impact of her health condition on our family. I closely experienced different aspects of informal caregiving, caregiver burden, the individual's struggle with depression, and lack of awareness among the families/caregivers. Up to one-third of the stroke survivors may later on get dementia (Mijajlović et al., 2017). This experience reinforced the relevance of my work of adapting and validating culturally appropriate cognitive assessment tools. I returned to Canada after a year and enrolled in the Interdisciplinary Rural and Northern Health program. During the first two years of my Ph.D, the whole focus was developing relationships with various stakeholders to adapt KCIA in Nepal. However, with the COVID-19 pandemic, my plan changed leading to shifting my research towards developing a functional assessment tool with Indigenous communities. I describe the process of shifting my research and building relationships in Chapter 3.

When I reflect on my journey of working in the rural and remote village in Nepal to the First Nations communities in Canada, I realize my passion for working closely with community people. Their stories, experiences, and shared wisdom have shaped my path. I am on a continuous journey of learning to become a better human being. The Ph.D. journey had its own ups and downs. COVID-19 and the invocation of a CCAA² process at my university in February 2021 were some of the unprecedented challenges. Despite these, I still consider this a beautiful journey. Recently, I presented my research approach and methods with my community-partner at the Annual Conference of International Indigenous Dementia Network

² The Companies' Creditors Arrangement Act (CCAA) is a federal law allowing insolvent corporations that owe their creditors in excess of \$5 million to restructure their business and financial affairs. The CCAA has a broad remedial purpose, allowing a company to continue in business while it seeks to develop and obtain the approval of compromises or arrangements with its creditors. Canadian courts have held that the main purpose of the CCAA is to avoid, where possible, the social and economic consequences of bankruptcy, and to allow a company to carry on business (Government of Canada, 2016)

in the beautiful native island of Hawaii. This accomplishment signifies more than academic achievement as it reflects the trust I've built with people I work alongside. Everyone's journey in this world is different. Reflecting on my Ph.D. path, five years ago, my expectations and principles were different as a new student and have changed so much. I anticipate this growth will continue to evolve over the next decade, enriched by the experiences I undergo and the relationships I cultivate. I will explain my relationship in terms of my research, supervisors, partner organization and research participants in upcoming sections of this thesis.

1.2 Background

Dementia is growing as an emerging public health concern worldwide. With the increase in the population aged 65 and above, dementia is anticipated to rise by 68% over the next 20 years in Canada (CIHI, 2020). The prevalence of dementia among the First Nations population in Alberta is 34% higher than the rates for the general population. By 2031, the number of First Nations people living with dementia is projected to increase four-fold (Jacklin et al., 2013a; Walker & Jacklin, 2015). Therefore, dementia has become a significant concern for Indigenous populations in Canada and beyond. Moreover, the legacy of colonialism and the intergenerational trauma embedded in the Indigenous population's socio-economic marginalization has compounded the complex health issues that further increase the risk of dementia (Petrasek MacDonald et al., 2018).

In addition to rising rates, Indigenous peoples experience dementia earlier than others (Jacklin et al., 2013b), and the rate is three to five times higher than the general population

(Radford et al., 2015). Despite this increase in Indigenous Peoples, dementia still goes unrecognized or overlooked in communities and by health care providers (Bryant et al., 2021). More often, dementia is not prioritized over other health issues in Indigenous communities. This is due to the limited access to appropriate health professionals and services and differing cultural understanding of dementia in the Indigenous communities (Petrasek MacDonald et al., 2018).

With the increase in the incidence and prevalence of dementia in Indigenous communities, there is a growing need for unique health care tools, services, and programs to support Indigenous individuals living with dementia, their care partners, advocates, families and communities. Generally, Indigenous people seek health care very late, with the average time between the onset of dementia symptoms and diagnosis being approximately 3.1 years (Speechly et al., 2008). Furthermore, Indigenous families and loved ones with dementia face discrimination and bias in dementia care systems, delaying dementia diagnosis and reducing their ability to access needed care and support (Halseth, 2018a). The literature shows that people basically seek services only once a crisis emerges (L. Flicker & Holdsworth, 2014). The lack of information and support for dementia care makes it harder for Indigenous Peoples to get assessed and diagnosed (Petrasek MacDonald et al., 2018).

Standard assessment tools help in the timely diagnosis of dementia and cognitive impairment; however, the validity and reliability of assessment instruments across cultures have been a continuing challenge as the existing tools often overdiagnose dementia in ethnic minorities (Parker & Philp, 2004). To address the related need for culturally safe dementia care resources, the *Canadian Indigenous Cognitive Assessment (CICA)* tool was culturally

adapted in collaboration with the First Nations communities on Manitoulin Island by Dr. Kristen Jacklin (Jacklin et al., 2020a) and tested for reliability and validity by Dr. Jennifer Walker (Walker et al., 2020). The *CICA* is a brief case-finding assessment tool intended to be used in Indigenous populations when cognitive impairment is suspected so that a complete dementia assessment can be prompted. It shows strong evidence of reliability and validity in detecting dementia but less accuracy in detecting mild cognitive impairment (Jacklin et al., 2020a; Walker et al., 2020). While the *CICA* addresses a key component of assessment, comprehensive cognitive assessment requires an evaluation of an individual's cognition and the functional impact of their cognition in daily life (Duong et al., 2017). The decline of daily function is a core component of the diagnosis of dementia and contributes to an individual's eligibility for services. Furthermore, functional decline profoundly impacts the quality of life of individuals and their care partners and the need for and use of health care resources (Giebel et al., 2015; Mlinac & Feng, 2016).

Functional decline can be assessed by measuring performance in activities of daily living, including Basic Activities of daily living (BADL), such as bathing, dressing and toileting and Instrumental Activities of Daily Living (IADLs), such as cooking, taking medications, housekeeping, using a phone and handling finances and shopping. Despite the cognitive impairment, most BADLs can be performed with the support of habits and routines (Sikkes et al., 2012); however, IADLs require multiple, simultaneous cognitive processes such as memory, attention, and executive functions (Sikkes et al., 2009). At the early stage of dementia, loved ones will have difficulty doing activities related to IADLs rather than BADLs. Thus, functional assessment to inform a dementia diagnosis should focus on

measuring IADLs, whereas measuring BADLs is relevant at a more advanced stage of dementia to inform the supports required (Chaves et al., 2011).

Various functional assessment tools are available to measure functional decline among loved ones; however, their application across diverse populations and cultures is limited. The approaches to measuring daily living activities developed in Western societies may not be applicable and relevant in different settings with different cultural expectations (Fillenbaum et al., 1978). It is necessary to ensure that the activities selected in the functional tool should be nearly universal to the population and have no cultural and gender biases.

Despite a lack of culturally-specific functional assessment tools, over recent years, other types of assessment tools for the Indigenous population have been developed using Indigenous approaches and methods recognizing that the worldviews and perspectives towards health differ among Western and Indigenous approaches. Despite strong Indigenous cultural understandings of ideal health being wholistic and ideal research being strength-based, literature on the health of Indigenous people has typically been described from deficit-based approaches (Hyett et al., 2019). Thus, we aimed to develop a functional assessment tool using Indigenous approaches centering the voices of the Indigenous population that is culturally appropriate, relevant and safe for First Nations communities to use while assessing function in relation to cognition. As a starting point for this journey of developing an Indigenous functional assessment tool, we focused on laying the foundation of developing an approach to functional assessment in collaboration with an Indigenous health organization.

1.3 Research Objective

During the validation of the *CICA*, which is a cognitive screening tool, the community advisory council and the clinicians involved in the process expressed the need for the development of an accompanying informant-based functional assessment tool to assist in the diagnosis of dementia (Walker et al., 2020). Because the diagnosis of dementia depends on both cognitive impairment and an impact on function, the combined use of these tools would provide a more comprehensive assessment of dementia, leading to better diagnosis. This would help Indigenous communities access timely, culturally safe, and relevant dementia care services.

Under the supervision of Dr. Jennifer Walker, I consulted with clinicians and Indigenous academicians to understand the need for an informant-based functional assessment tool in other Indigenous communities across Canada. They highlighted the need for an informant tool that focuses on the IADL aspect of function. Moreover, they stressed the importance of using Indigenous approaches to develop a culturally safe and relevant functional assessment tool. Thus, before developing a culturally-grounded functional assessment tool, I aimed to conduct a scoping review. The purpose of the scoping review was:

1. To identify approaches and methods that have been used to adapt and develop health assessment tools used for Indigenous populations across Canada, USA, Australia and Aotearoa/New Zealand.

Furthermore, I collaborated with an Indigenous health organization, Maamwesying North Shore Community Health Services, to design and conduct community-based participatory research. *CICA* training was being provided to the primary care providers of Maamwesying in different First Nations communities. Since Maamwesying provided health services to eleven First Nation communities, they wanted to develop a Memory Clinic that would provide comprehensive dementia assessment in the communities. After I presented the objectives and motivation of my study, Maamwesying expressed interest in partnership for this study. During our initial meetings, we discussed developing a functional tool, however, developing a new tool is itself a rigorous process that requires several steps with enough time and resources. As a starting point on this journey, due to the time and resource constraints of a Ph.D. student's project, I planned to conduct a preliminary study to lay the foundation for Maamwesying to develop the functional assessment tool. Thus, I aimed

2. To conduct a preliminary community-based study to inform the development of an Indigenous Functional Assessment tool, based on the learnings from objective one.

The preliminary study consisted of conducting focus groups with health professionals, both Indigenous and non-Indigenous, to combine their knowledge, experience, and perspectives and explore the domains of developing a culturally relevant and appropriate functional assessment tool, especially the IADLs. The research process was initiated by developing a Community Advisory Group (CAG) who was consulted at different stages of the research process. Similarly, the Senior Patient Advisory Group, who guides Maamesying, granted me permission to conduct my research.

1.4 Terminology

Numerous terms have been used to refer to the original people of North America, Australia, and Aotearoa/New Zealand. For this study, I was interested in the experiences of Indigenous people Canada, the USA, Australia and Aotearoa/New Zealand. In our scoping review, we referred to Indigenous people as defined by their own identity, such as ‘Aboriginal and Torres Strait Islander,’ ‘First Nations,’ ‘Métis,’ ‘Inuit,’ ‘Native American,’ ‘Native Hawaiian,’ ‘Alaska Native,’ and ‘Māori.’ To reflect a broader international perspective, we will use the term “Indigenous” as it is the most inclusive term.

The Canadian Constitution defines Aboriginal Peoples as including three groups: First Nations, Inuit and Métis (Government of Canada, 2021). The term ‘Indian’ has historically and legally been used to refer to First Nations people, but is considered offensive and is rejected as a state-created identity intended to perpetuate colonialism (Alfred & Corntassel, 2005).

“Loved ones” is used in this thesis to denote Indigenous people with dementia (Jacklin et al., 2015a). Mostly, I have used the term “loved ones” from the perspectives of family members or caregivers to refer to their beloved ones living with dementia. I have used “loved ones” in the text while writing from the perspectives of health professionals as well.

1.5 Thesis Structure

This thesis consists of five chapters: In the introductory chapter (Chapter 1), I position myself as a researcher, provide background and rationale for the objectives of the

research and discuss terminology. In Chapter 2, I provide an overview of the literature on dementia, its clinical presentation, and the relationship between cognitive and functional changes in the progression of dementia. In addition, I provide details on the prevalence of dementia at global, national, and provincial levels. I present an overview of the understanding of dementia in Indigenous contexts along with considerations for dementia diagnosis and caregiving in Indigenous populations. Furthermore, I provide details on the comprehensive assessment of dementia in Indigenous context, a discussion on the importance of developing an informant-based tool and the role of health professionals in dementia assessments. In Chapter 3, I describe the methodology chosen for this study, starting with an introduction of different worldviews that inform the work – my personal worldview, Western worldviews, and Indigenous worldviews. Further, I discuss the Indigenous Research paradigm and community-based participatory research and provide an overview of data collection and analysis techniques. The methods for conducting the two key components of the project, the scoping review and focus groups, are provided in detail. Next, Chapter 4 presents the results of the scoping review and the community-based focus group discussion. Lastly, Chapter 5 presents a synthesized discussion of the research findings, conclusions, limitations, and future research directions.

Chapter 2

2.1 Review of Literature

To provide a foundation for the proposed research, I will summarize the relevant published literature that describes dementia and the relationship between cognitive and functional changes that occur in dementia. I will present global, national and provincial data on dementia and describe the emergence of dementia as a priority in Indigenous contexts in Canada. This chapter further explores the literature on Indigenous perspectives and cultural understandings of dementia, challenges in diagnosing dementia and supporting care partners in Indigenous contexts, and governmental policies in relation to dementia in Canada. The literature summary provides the foundational information to understand the need of developing a functional assessment tool using Indigenous approaches and experiences of health professionals.

2.1.1 Dementia and its Types

Dementia is a syndrome characterized by the gradual and progressive deterioration of cortical functioning, including memory, language, judgment, comprehension, thinking, learning, executive function, complex attention, perceptual-motor and social cognition (American Psychiatric Association, 2013; World Health Organization, 2006). The decline in cognitive ability is severe enough to interfere with a person's social and occupational activities, especially everyday activities (Fymat, 2019). Moreover, the changes in these cognitive functions are followed by changes in behaviour, personality and mood fluctuations

(Ismail et al., 2016). Dementia is caused by various brain diseases and injuries (World Health Organization, 2023).

The Diagnostic and Statistical Manual of Mental Disorders- 5 (DSM-5) criteria has updated the definition of dementia and included it under Major Neurocognitive Disorders (MND) (American Psychiatric Association, 2013). MND is characterized by a significant decline in at least one of the domains of cognition which includes executive function, complex attention, language, learning, memory, perceptual-motor or social cognition. The decline represents a change from a patient's prior level of cognitive ability, is persistent and progressive over time, and is not associated exclusively with an episode of delirium. In addition to the cognitive decline, there must also be a decline in the patient's ability to function and perform everyday tasks. A patient's everyday activities are often evaluated in terms of the ability to perform complex IADLs, such as paying bills or managing medication, or, if more severe, BADLs, such as grooming or feeding oneself (American Psychiatric Association, 2013).

The DSM-5 criteria for major neurocognitive disorder include different etiological subtypes that indicate the possible etiology of the disorder. The most common subtypes are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy body disease (L. Flicker & Holdsworth, 2014; Hugo & Ganguli, 2014). Other less common causes include Parkinson's disease, Huntington's disease, alcohol-related dementia and traumatic brain injury (L. Flicker & Holdsworth, 2014).

Alzheimer's Disease is the most common type of dementia. It accounts for 60-80% of dementia cases, with slow and gradual cognitive decline (McKhann et al., 2011). This results

from a neuron and synapse loss, shrinking and damaging the brain (Alzheimer's Association, 2014). The first sign of Alzheimer's includes short-term memory loss followed by other cognitive impairments. These include memory loss, aphasia, agnosia, apraxia, disorientation and impaired visuospatial and executive function (Alzheimer's Association, 2014; Duong et al., 2017). Vascular dementia is the second most prevalent form of dementia, caused by reduced brain oxygen due to stroke or other conditions (Duong et al., 2017). It accounts for 20% of the cases and affects cognitive abilities, especially executive functioning. Lewy body dementia (LBD) is caused by abnormal deposits of alpha-synuclein protein (Lewy bodies) inside neurons affecting 5% to 15% of all dementias. It causes sleep, vision and movement problems (Alzheimer's Association, 2014; Duong et al., 2017). Frontotemporal dementia (FTD) damages the frontal and temporal lobes of the brain. It tends to occur at a younger age with most patients experiencing disease onset between the ages of 45 and 65 years (Chu et al., 2022). Other less common forms of dementia include Dementia Pugilistica, Creutzfeldt-Jacob disease, dementia associated with Parkinson's Disease; and Huntington's Disease (Thorgrimsen, 2016).

2.1.2 Clinical Presentation of Dementia

There are various types of dementia, and the clinical presentation of the disease varies according to the cortical areas involved. Across different stages of dementia, impairments in cognition and behaviour are observed, which leads to functional impairment. These symptoms usually appear gradually, and patients deteriorate over several years. As the disease progresses, clinical manifestations usually become more complex.

Reisberg (1982) described the course of dementia, especially Alzheimer's disease, in seven stages, from the normal stage to severe form, known as the Global Deterioration Scale (GDS) (Reisberg et al., 1982, 2010). In the first stage, there is no evidence of cognitive impairment and no problems with activities of daily living. In stage two, there is a subjective cognitive impairment with complaints of being forgetful, such as difficulties recalling names and/or misplacing objects. The third stage is characterized by mild cognitive impairment, with clinical evidence of a decline in social and occupational functioning. The earliest subtle deficits progress to mild dementia, where deficits are apparent on clinical examination and impair memory and the ability to deal with IADLs. From then on, cognitive losses become progressively more severe. There is a decline in the ability to function in daily and social activities, ultimately leading to complete dependence for care. During the progression of the disease, the deterioration of function occurs in five areas: concentration, recent memory, memory, orientation and functional activities (Reisberg et al., 1982, 2010; Rodríguez-Hidalgo et al., 2023).

A detailed history is essential for diagnosing dementia, as cognitive impairment is usually multifactorial. Clinicians gather information from the patient and collateral history from a reliable informant about the present history (detail, timing and progression of complaint), functional status (ADL), safety (driving, finances, ability to use appliances), medical history (cardiovascular disease, neurologic disease, history of head trauma or concussions) and social history (current living arrangement, support network) (Duong et al., 2017).

2.1.3 Cognitive Changes in Dementia

The major neurocognitive disorder characterized by DSM-5 corresponds to dementia, where evidence of a substantial decline in one or more cognitive domains from a previous level of performance is noted. Cognitive decline occurs in the following domains: complex attention, executive functioning, learning and memory, language, perceptual-motor/visuospatial function and social cognition (American Psychiatric Association, 2013).

Complex attention is a cognitive domain that involves controlling, shifting and dividing attentional focus, or sustained attention, selective attention, divided attention and processing speed (American Psychiatric Association, 2013; Dementia Australia, 2022). It allows manipulating information required to execute multiple steps to accomplish a goal. When complex attention is impaired, a person takes a longer time to do regular tasks, especially with competing stimuli such as difficulty watching TV, listening to the radio, or engaging in conversation. The person is easily distracted and has difficulty remembering or holding new information, such as recalling phone numbers or addresses and doing mental calculations. Executive ability includes planning, making decisions, responding to feedback or correcting errors, and using both working memory and mental flexibility (American Psychiatric Association, 2013). The person cannot perform familiar and complex tasks and projects at work and home. They need help performing multi-stage tasks, planning, organizing, multi-tasking and following directions to perform the work. Also, the person has difficulty keeping up with shifting conversations and usually must rely on others to plan IADLs or make decisions. They might also have problems with abstract thinking, display a

loss of initiative, and have poor/decreased judgment (Dementia Australia, 2022; Hugo & Ganguli, 2014).

During the impairment in learning and memory, there is deterioration in immediate memory, recent memory (free recall, cued recall and recognition memory) and long-term memory (American Psychiatric Association, 2013). The person repeats themselves in conversation, often with the same dialogue and cannot keep track of a shortlist of items when shopping or plans for the day. They require frequent reminders to orient the task, display confusion about time and place, and engage in repetitive behaviour. Language is another cognitive domain which is impaired in dementia. Language involves expressive language such as name, fluency, grammar, syntax, and receptive language (American Psychiatric Association, 2013). A person has significant difficulties with expressive or receptive language. Instead of using the actual term, they may use general terms such as ‘that thing’ and ‘you know what I mean.’ As the impairment worsens, they may not recall the names of close friends and family.

Perceptual-motor-visual perception includes visual perception, visuoconstructional reasoning and perceptual-motor coordination (American Psychiatric Association, 2013). It involves picking up the telephone, handwriting, and using a fork/spoon. An individual may have difficulties with previously familiar activities (using tools, driving a motor vehicle, and navigating in familiar environments). Social cognition involves recognizing emotions and behavioural regulation, (American Psychiatric Association, 2013). It involves activities such as social appropriateness in terms of dress, grooming and topic of conversation. The individual may have changes in behaviour, such as showing insensitivity to social standards

or making decisions without thinking of safety issues. The person becomes socially withdrawn or isolated (American Psychiatric Association, 2013).

2.1.4 Functional Changes in Dementia

Changes in functional abilities are essential manifestations of dementia. The changes in the functional abilities that interfere with everyday activities necessary for independent living are part of the diagnostic criteria for dementia (American Psychiatric Association, 2013). Different cognitive (reasoning, planning), motor (balance) and perceptual (sensory) functions are involved while performing the basic and instrumental activities of daily living (Cipriani et al., 2020).

While functional decline is thought to occur only after cognitive deficit, studies suggest that subtle functional decline occurs even in cognitively normal individuals who later progress to mild cognitive impairment of Alzheimer's disease (AD) (Weintraub et al., 2018). Verlinden and colleagues (2016) found "earliest symptoms 16 years before dementia diagnosis, initiating with memory complaints, followed by a decline in mini-mental state examination, then instrumental activities of daily living, and finally basic activities of daily living" (p. 152). Generally, functional impairments begin when cognitive impairment is mild and noticeable in complex occupational tasks such as work, hobbies and social activities. It is observable that with mild cognitive impairment, people start missing appointments and finding difficulty in unfamiliar environments (Gélinas, 1995). With the progress to mild cognitive impairment, people have more difficulty performing complex IADLs like dealing with finances or shopping. This will cause problems with living alone; however, people can

still perform basic tasks such as dressing or walking in the neighbourhood. As cognitive impairment becomes moderately severe, BADLs are impacted. People will have difficulty choosing appropriate clothing concerning occasion, neatness, weather and colour combination as well as in appropriate order. Driving and using public transportation alone can carry risks. As the disease progresses, the individual loses the ability to dress, bathe, and toilet and eventually loses speech and locomotion abilities. In this stage, the individual is severely cognitively impaired and needs ongoing care (Gélinas, 1995).

2.1.5 Relationship Between Cognitive Decline and Functional Impairment in Dementia

Cognition refers to the mental processes of thinking, remembering, judging and problem-solving in gaining knowledge and comprehension. These cognitive domains are closely associated with the ability to perform everyday functions (Hugo & Ganguli, 2014). There is a positive correlation between cognitive and functional performance; that is, cognitive decline affects functional dependence in a person with dementia (Millán-Calenti et al., 2012). However, research suggests that despite early dementia detection through tests, patients may not necessarily experience difficulty in their daily routines (Cipriani et al., 2020). Thus, it is essential to understand the correlation between the performance of cognitive test and the functional ability of an individual.

A study by Ishizaki et al. (2006) reported that participants with cognitive impairment were four times more likely to show functional dependence on BADLs and six times more likely to present dependence on IADLs. In addition, Millán-Calenti et al. (2012) reported that “cognitive impairment had a strong effect on the dependence on the execution of everyday

activities, basic and instrumental, independently of age, gender, educational level and health condition” (p. 200). However, in their study, the degree of cognitive decline affected functional disability in BADLs and IADLs differently (Millán-Calenti et al., 2012; Njegovan et al., 2001). A hierarchy exists in the loss of capacity to execute everyday activities as the cognitive deficit progresses. Impairment in IADLs are observed in mild stages of cognitive decline, whereas challenges with BADLs appear in more progressed and severe cognitive impairment. This means that a person loses the ability to perform these activities in the opposite order to what they acquired during childhood (Njegovan et al., 2001). Thus, those unable to perform BADL tasks are also unable to execute IADL independently (Millán-Calenti et al., 2012). As such, IADL impairment is more useful than BADL impairment as an indicator to inform early dementia diagnosis.

Executive function and memory are related to functional limitations. Those with executive dysfunction will likely have difficulty executing complex tasks such as following medication regimens, preparing meals with multiple ingredients and steps and balancing a cheque-book. The frontal lobe, the prefrontal cortex, is associated with the successful completion of goal-directed behaviour, and damage to this lobe affects IADLs such as using transportation, managing finances, and organizing household activities (Cipriani et al., 2020; Marshall et al., 2011).

2.1.6 Global Prevalence of Dementia

Globally, the population is aging. The primary drivers of aging of the population worldwide are improved life expectancy and decreased fertility rates (World Health

Organization and US National Institute on Aging, 2011). In 2019, the number of older adults aged 65 and older was 703 million, and it is projected to double to 1.5 billion by 2050 (United Nations, Department of Economic and Social Affairs, Population Division, 2019). The global share of the population aged 65 and above increased from 6% in 1990 to 9% in 2019 and is projected to rise further to 16% in 2050. Thus, it is expected that one in six people worldwide will be 65 years and older by 2050 (United Nations, Department of Economic and Social Affairs, Population Division, 2019).

Dementia is an emerging international health problem. It is estimated that 55 million people worldwide are living with dementia in 2020. This number will almost double every 20 years, reaching 78 million in 2030 and 139 million in 2050 (Alzheimer's Disease International, 2023). Among them, 60% of all people with dementia live in low-and middle-income countries (LMIC), rising to 71% by 2050. Although there is a similar pattern in increases in diagnosed dementia cases around the world, the rate of increase varies from region to region. Between 2015 and 2050, the number of dementia in high-income countries will increase by 116%, in upper middle-income countries by 227%, in LMIC by 223% and low-income countries by 264% (Prince et al., 2015). It is estimated that there will be over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds (Prince et al., 2015).

2.1.7 Dementia Prevalence in Canada

In Canada, the population aged 65 and over is increasing. As of July 2022, an estimated 18.8% of the population was over 65 (Statistics Canada, 2022a), representing

almost one in 5 Canadians, an increase of 1.9% since 2016. This proportion is expected to increase to between 21.6 (slow-aging scenario) and 29.8% (fast-aging scenario) in 2068 (Statistics Canada, 2019). The proportion of Canadians living with dementia is projected to rise with the increase in the older population, as dementia is an age-related disease. The prevalence of dementia has increased steadily over the past 20 years in Canada from 0.14 in 1994 to 0.80 in 2014 with 0.66 point increase (Chambers-Richards et al., 2022). This increasing trend in prevalence was observed across all ages, sex, education and region of residence. A study by Bronskill et al. (2016) on the trends in dementia showed a slight decrease in incidence and mortality from dementia. A study by Singh et al., (2023) using the Canadian Community Health Survey (2016-2021) data reported an increased prevalence of self-reported dementia from 2018 to 2021 in people living in the community.

In 2020, it was estimated that 597,300 individuals were living with dementia, which is expected to reach close to 1 million by 2030 (Alzheimer Society, 2022). The annual incidence of dementia in 2020 was 124,000, which was 10,333 per month, 348 per day and 15 new cases every hour. By 2030, this is supposed to rise to 187,000 new cases a year, which will be 15,583 per month, 512 per day and 21 new cases every hour (Alzheimer Society, 2022).

In Canada, the age-specific prevalence of dementia doubles every five years for those aged 65 and older, from less than 1% for those aged 65 to 69 to about 25% for those 85 and older. Dementia is more prevalent among women than men, and the gap increases with the age of those aged 65 years and older living with diagnosed dementia in 2015-2016, 63% were women (CIHI, 2020). Women have higher rates of Alzheimer's disease, while men

have higher rates of other types of dementia, such as frontotemporal and Lewy body dementia (Podcasy & Epperson, 2022). The prevalence of dementia varies across provinces and territories. It is estimated that the total annual health care costs for Canadians with dementia will double from \$8.3 billion to \$16.6 billion by 2031 (Alzheimer Society Canada, 2016).

2.1.8 Dementia Prevalence in Ontario

A study by Bronskill et al. (2016) using Ontario population-health administrative data from 2004/05 to 2021/13 reported an increase of age and sex-standardized prevalence of dementia of 18.2% (from 63.0 to 74.5 per 1000 persons) for individuals aged 66 years and older. Conversely, the age and sex standardized incidence decreased slightly from 18.2 to 17.0 per 1000 persons (Bronskill et al., 2016). The same study showed that the prevalence rate was higher among women than men; however, the increase in the rate over time was greater among men. Another study using administrative health data in Ontario among people living in the community showed an increasing dementia prevalence and decreasing incidence between 2010 to 2015 (Vanderkruk et al., 2020). The average annual prevalence growth among people living in the community was 1.6% per year whereas an average annual incidence decline of 2.6% per year was noted from 2010-2015 (Vanderkruk et al., 2020).

Ontario is one of the fastest-growing and youngest provinces in Canada. By 2050, it is projected that Ontario will see a 202% increase in the new cases of dementia, among which 1.5 million will be new cases of AD, 680,000 new cases of vascular dementia and 780,000 new cases of other types of dementia (Alzheimer Society, 2022). Although dementia

is most common among people over 65, almost seven percent of dementia diagnoses in Ontario are between 40 and 65 years old. Moreover, about 64% of people diagnosed with dementia were women (Ministry of Health and Long-Term Care, 2016). The increase in the prevalence of dementia over time may be attributable to the continued increase in the size of the older population, growing awareness of the disease and earlier diagnosis of cognitive deficits (Chambers-Richards et al., 2022).

In summary, the overall data showed an increase in the prevalence of dementia at global, national and provincial levels. However, the incidence of dementia seemed to decrease slightly in high-income countries.

2.1.9 Indigenous Peoples and Dementia

According to Statistics Canada, in 2021, there were 1.8 million Indigenous people in Canada, accounting for 5% of the total population, up from 4.9% in 2016 (Statistics Canada, 2022b). Indigenous populations grew by 9.4% from 2016 to 2021 compared to 5.3% for non-Indigenous Canadians. Indigenous populations are younger on average than non-Indigenous populations; however, the share of Indigenous people aged 65 years and older continues to grow. From 2016 to 2021, the proportion of Indigenous people aged 65 and older rose from 7.3% to 9.5%. As of 2021, one in six First Nations people is now 65 years and older (Statistics Canada, 2022b).

Advancing age increases the risk of dementia. Age-related dementia has been an emerging concern for Indigenous people worldwide, and the incidence, as well as prevalence of dementia, is higher in Indigenous compared to non-Indigenous populations (Warren et al.,

2015). Evidence suggests a substantial increase in the prevalence of dementia among Indigenous people in Canada. Although Indigenous health organizations in Ontario have been noticing the rise in the rate of dementia since 2007, data relating to dementia among Indigenous peoples in Canada are still limited (Sutherland, 2007). A study by Jacklin, Walker and Shawande in 2013 suggested the age-standardized rate of dementia was 34% higher in First Nations than in non-First Nations populations in Alberta, and the rates are also rising more quickly. The same study reported that First Nations people had a younger onset of dementia, and that the prevalence was higher in males (Jacklin et al., 2013a).

Evidence suggests age-related dementia is considered a newer illness, which has recently become more common in Indigenous populations (Jacklin & Walker, 2020; Webkamigad et al., 2020). With improvements in life expectancy and an increasing number of older populations, Indigenous populations are more likely to experience dementia. Nevertheless, with the existing multiple chronic conditions and other health issues being a priority, dementia in Indigenous populations is often undiagnosed or diagnosed at later stages (Petrasek MacDonald et al., 2018). Traditionally, there have been relatively smaller older Indigenous populations in North America, and the rate of dementia was low; however, the current scenario looks different (Jacklin & Walker, 2020). As the rate of dementia is rising rapidly among Indigenous people, combined with age shifts in the population, it is estimated that there will be a four-fold increase in the number of Indigenous people with dementia by 2031 (Walker & Jacklin, 2019). In Alberta, the rate of dementia in the First Nations population grew from 3.9% per 1000 to 7.5% per 1000 between 1998 and 2009, which is higher than the rate of dementia in the non-First Nations population (Jacklin et al., 2013b).

Similarly, the rate of dementia in the First Nations population in BC also rose from 4 to 6 % per 1000 population between 2002/3 and 2006/7 (British Columbia Provincial Health Officer, 2009). The rate of dementia in Indigenous peoples in Canada is expected to grow more rapidly than among non-Indigenous people. Apart from the demographic shift of the growing elderly population and higher rates of associated diseases such as cardiovascular disease and diabetes, there are other physiological and social factors associated with the higher rates of dementia in an Indigenous population (Jacklin et al., 2013b).

2.1.9.1 Indigenous Perspectives and Cultural Understandings of Dementia

Although the biomedical understanding of dementia in the Indigenous population is spreading, knowledge about Indigenous people's experience with dementia is limited (Jacklin et al., 2013b; Jacklin & Walker, 2012). Indigenous cultures and belief systems across North America vary, and each community has their understanding of health, aging and memory loss. Similarly, Indigenous Peoples across Australia view dementia as a natural part of the life cycle rather than an illness that must be fixed, as long as the individual, family and community are safe and the illness does not affect the connection to family, community and culture (Alzheimer's Australia, 2006).

Earlier research on dementia with Indigenous people was conducted from biomedical concepts of dementia, which differs from how many Indigenous people perceive health and wellness. Over recent years, with increased Indigenous self-determination in research, Indigenous frameworks have been used to research dementia in Indigenous populations. Many First Nations communities in Canada perceive dementia as a "natural," "normal," and

a part of the “circle of life” (Hulko et al., 2010; Jacklin & Warry, 2012; Lanting et al., 2011). Some First Nations communities even describe dementia as “going through the full circle of life” (Hulko et al., 2010) or being “closer to the Creator” as part of a natural life cycle and a return to the stage of infancy (Sutherland, 2007). Although dementia may be viewed as normal by Indigenous communities, community people also report feeling unprepared to care for their loved ones in the later stage of the illness (Hulko et al., 2010; Sutherland, 2007). Indigenous family members and caregivers lack knowledge about dementia, including information about risk factors, symptoms and treatments (Finkelstein et al., 2012; Jacklin et al., 2015b; Pace, 2013a). Research on healthy aging, dementia prevention, and care in the Inuit population is emerging (Halseth, 2022). The experience of dementia, prevention and care for Inuit people are deeply connected to place and culture (Pace, 2016). The concepts of personhood and the significance of relationships to place, culture, and the natural world play an essential role in the health and wellness of the Inuit population (Pace, 2020). There has been no publication on the Métis perspectives and cultural understanding of dementia (Jacklin & Walker, 2020).

2.1.9.2 Diagnosing Dementia in Indigenous Population

Dementia is more likely to be undiagnosed or delayed in diagnosis in non-White or minority older adults in the USA (Amjad et al., 2018). Despite the need for recognition and diagnosis of dementia in Indigenous populations, Indigenous people often go undiagnosed due to various challenges (Petrasek MacDonald et al., 2018), such as lack of awareness and knowledge about dementia, lack of specialist care, travel to urban centres to access

specialized health care services and use of inappropriate diagnostic tools (Halseth, 2018a). If diagnosed, it is often in the late stage as multiple chronic conditions are prioritized over dementia (Halseth, 2018a; Health Council of Canada., 2013). These challenges impact the timely diagnosis of dementia, delay access to care and services related to dementia and impact the quality of life of people with dementia (Pace et al., 2013). Indigenous people often live in rural and remote areas without access to specialists, as it is more challenging and expensive to provide specialized care in such communities (Andrews et al., 2010). Due to limited availability of health services in rural and remote communities, older people are often compelled to travel to urban centres to access specialized care and services. This can lead to the financial burden, stress or anxiety and physical discomfort (Morgan et al., 2009). Thus, the above-mentioned factors can result in a delayed diagnosis and impair quality of care, impacting the health of an individual, and their quality of life (Dal Bello-Haas et al., 2014; Morgan et al., 2009; Pace, 2013b). In a place where specialized care is available and accessible, Indigenous people, due to their prior experience with racism and discrimination within the health care system, often underutilize the existing care due to the fear and mistrust of the Western health system or health care personnel (Finkelstein et al., 2012; Phillips-Beck et al., 2020). Thus, health care providers need to understand the historical experiences and the lived experiences of Indigenous people to care for themselves or access health services that are effective, sensitive, and provide quality care (Alcock, 2014).

Indigenous people often face challenges accessing culturally safe and appropriate dementia care services (Chakanyuka et al., 2022; Halseth, 2018b). This is due to the lack of appropriate diagnostic tools for Indigenous populations (Jacklin et al., 2020b; Walker et al.,

2020). Most cognitive and functional assessment tools required to assess dementia have been developed and validated for White, English-speaking, educated and urban-based individuals (Ng et al., 2018; Walker et al., 2020). Using such tools in the Indigenous context is problematic in content and is linguistically and culturally biased. These tools fail to account for the cultural differences and intentionally or unintentionally impose Western values, beliefs, and care systems upon Indigenous people, further perpetuating colonization (Peters & Peterson, 2019a). There are differences between Indigenous and Western worldviews. Western ideology is based on individualism, rationalism, dualism, universal truth, and objectivity, which is often incompatible with Indigenous beliefs of collectivism, relationality, subjective knowledge, and multiple truths and realities (Peters & Peterson, 2019a). Without specific cognitive and functional assessment tools developed for Indigenous people, clinicians may rely on standardized and informal assessments. These tools are mostly used without verifying the reliability and validity of their modifications in an Indigenous context (Dingwall et al., 2013a; Walker et al., 2020). Assessment tools developed and validated in distinct cultural contexts produce inaccurate assessment results when used elsewhere (Acevedo-Polakovich et al., 2007).

Over decades, researchers have been adapting and developing culturally appropriate assessment tools specifically for the Indigenous populations. Tools such as the *Grasshoppers and Geese test* (Lanting, 2011) and the *Canadian Indigenous Cognitive Assessment (CICA)* (Jacklin et al., 2020a) tool have been adapted and developed in the Indigenous context following the Indigenous research approaches and methods. *CICA* has been considered a reliable and valid cognitive assessment tool that is culturally grounded and appropriate for

First Nations communities and is being adapted in other Indigenous communities across Canada (Jacklin et al., 2020a; Walker et al., 2020). Developing and providing culturally appropriate and safe care helps to overcome the barriers preventing Indigenous people from accessing the required health services and to address the ongoing health disparities.

2.1.10 Comprehensive Assessment of Dementia

The National Institute of Aging- Alzheimer' Association (NIA-AA), DSM-IV (American Psychiatric Association, 1994), DSM-5 (American Psychiatric Association, 2013) criteria for diagnosing dementia require not only deficits in cognitive function, but also a decrease in daily, social and occupational function. As noted previously, IADLs require complex cognitive processing and impairments in IADL are an early feature of dementia. Thus, measuring IADLs for functional decline is crucial in the early diagnosis of dementia.

Although a culturally appropriate and safe cognitive assessment tool (*CICA*) was developed using community-based approach on Manitoulin Island with Anishinaabe communities, a similar tool to assess functional aspects, especially IADLs, in Indigenous contexts is lacking. While validating *CICA*, the community advisory council and the physician involved in the process, recognized the need for the development of an informant-based functional assessment tool in the Indigenous context (Walker et al., 2020).

For a long time, it was believed that functional impairment occurs only after cognitive decline. However, evidence suggests that subtle functional decline occurs even in cognitively normal individuals who later progress to mild cognitive impairment or dementia (Dubbelman et al., 2020; Sikkes et al., 2011; Weintraub et al., 2018). This might indicate that

these individuals have a lower level of functioning from earlier, or the functioning declined in the pre-dementia stage (Dubbelman et al., 2020). A study by Dubbelman et al. (2020) reported that functional decline co-occurs with the earliest changes in cognition, revealing the importance of assessing daily functioning in addition to cognitive functioning, particularly in early stages. Dubbelman et al. (2020) even suggested combining IADL measures with sensitive cognitive tests for detecting such changes. Such evidence has further emphasized the need for reliable, sensitive and valid IADLs tools to be used for assessing dementia in its early stage. IADLs are important for both individuals and families to live a life of autonomy and independence and are related to quality of life.

Several tools are available for assessing functional decline; however, some of these tools measure both BADLs as well as IADLs aspects without distinguishing them. Very few functional assessment tools measure only IADLs aspects, such as *Lawton and Brody Instrumental Activities of Daily Living* (Lawton & Brody, 1969) and *Functional Activities Questionnaire* (Pfeffer et al., 1982), and *The Instrumental Activities of Daily Living Profile* (Bottari et al., 2010). However, these tools rely on self-reporting, which introduces bias as individuals may either overestimate or underestimate their capacities when assessed on their own (Rueda et al., 2015). The *Amsterdam IADL Questionnaire* (Sikkes et al., 2012) is an informant-based instrument developed to assess complex everyday activities that help in diagnosing dementia in early stages. It was developed in Amsterdam and consists of a 70-item informant-based computerized questionnaire. However, it has not yet been validated in Indigenous populations. The 5th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD) recommends using *Functional Activities Questionnaire*

(FAQ) or the *Disability Assessment for Dementia (DAD)* (Ismail et al., 2020). The FAQ is a self-reported IADL measure while DAD (Gélinas, 1995) consists of both BADL, IADL measure along with assessments related to leisure, initiation, planning and organization and effective performance.

While everyday function closely relates to our daily lives, IADLs may be subjected to bias caused by factors such as age, gender and cultural difference. The ability to conduct IADLs are not only determined by the physical ability of an individual but also influenced by the environment and cultural context (Nikula et al., 2003). Studies have shown IADLs activities such as cooking, cleaning, driving, and handling finances have culture and gender-specific biases (Kim & Won, 2020). In some cultures, older adults are not expected to clean, cook or make appointments with doctors, which are the responsibility of younger family members. In Indigenous communities, older adults often live with or close to family and family are there to support the older adults (Habjan et al., 2012). Throughout history, Indigenous women have been influential as matriarchs, responsible for guarding cultural and tribal traditions (Bingham et al., 2019). Some older Indigenous people are recognized as Elders when they have dedicated their lives to learning and living in Indigenous ways (Tonkin et al., 2018; Viscogliosi et al., 2020). They are teachers and knowledge carriers, and families and community members are responsible for taking care of their needs. In general, one of the important roles of older Anishinaabe people is to impart knowledge and wisdom to younger generations (Rowe et al., 2020). For that reason, instead of IADLs emphasizing financial management or household chores, social activities such as overseeing ceremonies,

or guiding local affairs may be better to consider when testing for cognitive and functional decline (Yemm et al., 2021).

Within a country and between communities, socio-economic status, social setting (rural and urban), or gender roles may contribute to differences in the activities of daily living. Thus, IADL tools developed for a population in one setting may therefore not assess the same parameters for a population in another setting (Mathuranath et al., 2005). Not surprisingly, concerns have been raised over the accuracy or appropriateness of such tools in distinct cultural contexts, as such tools have the potential to produce inaccurate assessment results, potentially causing harm (Acevedo-Polakovich et al., 2007). Further, use of Western-based tools intentionally or unintentionally imposes Western values, beliefs, and care systems upon Indigenous people and serves as a further means of colonization (Peters & Peterson, 2019b). Thus, while selecting IADL assessment tools, cultural appropriateness for the target population is crucial to enhance efficacy and accuracy. The cultural expectations of the target population need to be considered, and the assessment must reflect the activities of older adults within that culture (Magklara et al., 2019).

A systematic review by Sikkes et al. (2009) of 12 IADL tools revealed that the psychometric properties of many tools, such as content validity, internal consistency and reproducibility, are lacking (Sikkes et al., 2009). Sikkes et al. (2009), criticize that most of the tools were developed before 2000, and as a result, they do not address questions related to modern technology commonly used in our daily lives, such as use of mobile phones, computers and household appliances. They emphasized the importance of considering these factors in the current context while developing new assessment tools (Sikkes et al., 2012).

2.1.11 Importance of Developing Informant-based Tool

IADLs are measured using three methods: self-report by the individual, performance-based assessment and informant report (Sikkes et al., 2012). Self-report is the simplest method but may be invalid when individuals with cognitive impairment have impaired insights (Graham et al., 2005; Sikkes et al., 2012). Performance-based assessment provides an objective-behavioural evaluation, but it is time-consuming, costly and limited in activities assessed. In addition, patients' performance may vary between clinical settings and their performance at home (Loewenstein & Acevedo, 2009; Sikkes et al., 2012). Informant report is the third assessment method and involves interviewing a spouse, partner, relative or close friend. It relies on observant collateral sources and assesses both cognitive and functional changes. Moreover, it is unaffected by the educational background and the premorbid ability of an individual being assessed (Galvin, 2018). Informant reports are widely used in dementia evaluation due to their simple administration, real-world functional performance of IADLs, and reduced burden on patients. Sikkes et al. (2012) noted that informant reports provide an accurate overall estimate of a patient's functional status because the informant has had an opportunity to observe their loved one's function over long periods and through varied interactions. However, it logically follows that the closeness and time spent with the informant might influence the reliability of the results (Galvin, 2018); for example, there may be differences in accuracy between an informant who lives with the patient and a caregiver who visits their loved one on an irregular basis.

2.1.12. Role of Health Care Professionals in Dementia Assessments

Diagnosing dementia involves assessing cognitive decline and impairments in daily activities, relying on medical history, information from family members, friends or caregivers, and using cognitive and functional tools, laboratory tests and brain imaging (Arvanitakis et al., 2019). In Canada, family physicians are the first contact point, being responsible for dementia assessment, requesting diagnostic tests, drug prescriptions, and referrals to specialists when necessary. Despite having a higher number of family doctors, Canada has a lower specialist density per capita among G7 countries, leading to longer wait times for specialized services (Lee et al., 2018). Rural and remote areas face substantial challenges in terms of timely access to care and experience long wait times for both physicians and specialists due to the uneven distribution of primary health care services among large geographical areas (Shah et al., 2017).

To address this issue, the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD) recommended shifting the responsibility for diagnosing and managing dementia to primary health care (Moore et al., 2014). The 5th CCCDTD suggested that primary care clinicians can diagnose most forms of dementia (Ismail et al., 2020), emphasizing that patients with cognitive decline should be primarily managed in family practice, except for unusual or rapidly progressive cases (Moore et al., 2014). Concerns have been raised about the ability of family practitioners about their lack of knowledge and preparedness to assess and manage early cognitive and functional decline (Aminzadeh et al., 2012; Crowell et al., 2020). The proficiency of family practitioners in assessing cognitive and functional complaints varies, with younger physicians more likely to

be using standardized protocols and those with more experience relying more on flexible approaches and support staff. Despite these variations, experts believe that dementia is often undiagnosed and is usually diagnosed in its later stages (Mattke et al., 2021).

Developing simplified cognitive and functional assessment tools for early-stage symptoms and integrating them into widely used electronic health records is an effective approach for dementia assessment in primary care (Mattke et al., 2021). The use of better tools helps streamline procedures in family practice, allowing support staff to manage specific tasks and reducing the burden on specialists for dementia diagnosis. Canada was one of the first countries to initiate primary care-led memory clinics (Lee et al., 2014). Primary Care Collaborative Memory Clinics (PCCMCs) originated in 2006 in Ontario to address the limited capacity of specialists in dementia care (Crowell et al., 2020). PCCMCs consist of a multidisciplinary team of one or two primary care practitioners (PCPs), two to three nurses, a social worker, and administrative staff. Depending upon the availability of resources, some PCCMCs include a pharmacist, an occupational therapist, and representatives from the local Alzheimer's disease association to provide additional information, education, and support to patients and their caregivers. PCPs lead the routine operations of the PCCMCs and designated specialists are available for consultation at memory clinics via telephone or email. This significantly reduces the wait times for patients as the specialists are referred only for complex cases (Lee et al., 2018). This suggests that a diverse group of primary care health professionals are involved in detection, diagnosis and care of patients with dementia in Canada.

Despite the availability of various diagnostic tools for dementia, screening individuals with memory complaints for cognitive and functional decline at the community level remains one of the best options for early detection. When developing such tools in Indigenous contexts, cultural aspects must be respected and integrated for both cultural safety and the psychometric strength of the tools. In the absence of culturally appropriate and relevant tools for Indigenous communities, health professionals are obliged to use tools developed in Western contexts. Although a culturally grounded informant-based tool is much needed, it is important to understand the perspectives of health care professionals about the necessary aspects of cognitive function that are important to include in Indigenous-specific tools because they are responsible for conducting cognitive and functional assessments and have substantial experience with using both mainstream and informally adapted tools. Thus, I aimed to conduct a preliminary study to understand the perspectives of health care professionals regarding their experiences and challenges in assessing function in Indigenous communities, and the domains that need to be considered in an informant-based functional assessment tool.

Chapter 3

3. Methodology and Methods

This chapter will describe the process that was used to generate shared knowledge and understanding to lay the foundation for developing a functional assessment tool for diagnosing dementia in Anishinaabe communities. To do this, I adopted several strategies that will be described in more depth throughout this chapter. These strategies included the following. First, this research was informed by Indigenous epistemologies, ontology, axiology and methodology, which foreground Indigenous Peoples' perspectives and knowledge and are inherently oriented towards ethical issues and equity. Second, the process of research, including the development of the research objective, rationale, data collection and analysis, was conducted in partnership with Maamwesying North Shore Health Services, a Community Advisory Group (CAG) and Indigenous and allied academic supervisors who have extensive working with Indigenous communities. Third, the research process was conducted with broad engagement with Anishinaabe community members and Elders, health care professionals, and health system leaders. Fourth, the research protocol included seeking institutional and organizational research approval in advance of recruiting and seeking consent of individuals. Fifth, given the inherent power imbalances between academic researchers and Indigenous communities, the research partnerships were established to mitigate potential harms to Indigenous communities to the extent possible as well as to promote the uptake of the research findings. As part of this partnership, Maamwesying intends to use this research to form a foundation that they will take forward to further

develop an Indigenous Functional Assessment tool. I have followed (Wilson, 2008) Indigenous Research Paradigm as a framework for this study. In the first section, I will describe the personal worldviews that shaped my values, beliefs, concepts, experiences, perceptions, personality, and exposure to Indigenous worldviews.

3.1 Worldviews

Worldviews are the mental lenses ingrained in how we perceive the world (Olsen, 2019). These are the cognitive, perceptual and affective maps that people use constantly to get a sense of their social surroundings and to find their way toward the goal they seek. Worldviews help us understand the world daily by influencing reasoning and perceptions, informing our decision-making, and providing a reason for existence and a role in the world (Fisher, 2012). Whether people recognize and articulate it or not, each individual has a personal worldview (Christian, 2009). Worldviews generally develop over time based on our experiences through social interaction and socialization. Education, personal, social, cultural and religious experiences and expectations of society play a role in developing worldviews (Fisher, 2012). They are usually internalized, unquestioned and uncritically taken for granted as the way things are (Olthuis, 1985). Although worldviews rarely modify significantly, they can slowly change over time and can be communal and personal. Furthermore, it offers a view of life and a vision for life by proposing ethical and moral standards and values. Although most members hold a dominant worldview in any society, alternative worldviews exist too. In today's world, Western worldviews dominate despite the existence of diverse

worldviews. While conducting research, it becomes crucial to embrace both the worldviews of the community with whom we are working and ourselves (Hart, 2010).

In the section below, I will provide detail about my personal worldviews as they differ from the Anishinaabe worldviews in the communities where I am conducting my research. In addition, I will provide details on how my worldview was shaped in the process of my academic journey and my understanding of Indigenous worldviews in relation to this research. Reflecting on my personal worldviews helped me to contextualize my beliefs, values, opinions, concepts, experiences and perceptions within the present landscape of Indigenous research and guided me towards taking positive actions rather than doing harm.

3.1.1 My Personal Worldviews

My worldviews are influenced by various elements such as family, community, education, life experiences, religion, customs, and beliefs. I was born into a traditional Hindu family in a suburban area of Nepal. Hinduism is a complex amalgamation of religious, philosophical and cultural ideas and practices that are the foundation of our social, political, cultural, religious and spiritual beliefs (Jaiswal, 1991). In contemporary discourse, Hinduism is projected more as a religion and political agenda; however, for us, it is a way of life deeply rooted in the rich tapestry of the Indian subcontinent. Western concepts of faith comprise dogmas and creeds; however, in Hinduism, religion is a way of life based on realization and experiences. As philosophy, religion, and spirituality are intricately intertwined and inseparable (Gill, 2006), this perspective profoundly influenced my worldview.

Like many Indigenous cultures, my values are passed down orally through generations. Instead of rulebooks, as in different cultures, we rely on scriptures that impart values through stories and cultural events. Epics such as Ramayan and Mahabharat, ceremonies, occasions and festivals transmit values, morals and lessons to the younger generations based on elder beliefs (Aten, 2008). These values and morals are drawn from the stories from these scriptures, which the grandparents share with grandchildren. Various deities represent symbols related to these stories and teachings, forming the bedrock of our moral and ethical compass.

I remember my grandfather telling us to take every challenging work as if I was just playing games. Also, he used to tell me that gaining knowledge and wisdom is like doing penances. Such teachings have influenced my life at large. These days, when I go back to Nepal, my father-in-law narrates stories from the epics with my son. These stories have profound lessons, and as this has helped me navigate society's complexities, my son will also reflect on these stories and move ahead in his life.

Hindu philosophy seeks knowledge that cultivates a holistic understanding of humans, the cosmos and ultimate reality (Gill, 2006). It differs from Western philosophy, which emphasizes scientific principles and measurable methodologies. On the contrary, Eastern epistemology acknowledges our innate sense of knowing, inner consciousness and spiritual components as fundamental to knowledge (Deutsch & Dalvi, 2004). Among Eastern philosophies, there are different thoughts of schools that express diverse views, yet all advance a holistic and integrated outlook. While Western worldviews are characterized as

rational, materialistic and extroversive, Eastern worldviews, including Hinduism, are identified as intuitive, spiritual, mystical and introversive (Gautam & Luitel, 2013).

3.1.1.1 Education's Role in Shaping My Worldview

As worldviews develop throughout a person's lifetime due to social, personal and cultural experiences, my worldview is an intricate blend of cultural beliefs, emotional experiences, social interactions, religious upbringing, family structure and education. Education has played a pivotal role in shaping my worldview and personality.

In Nepal, where I spent most of my life and completed my education up to the Master's level, the education system predominantly reflects Western traditions. Initially, the education system was primarily influenced by British colonialism, and subsequently, American traditions were grounded in Western knowledge, often prioritizing Western worldviews (Rai & Gaire, 2021). This Western worldview spread during the Enlightenment era with the belief in ontology of materialism and objectivity as epistemology disregarding Indigenous and non-Indigenous knowledge (Luitel & Taylor, 2019). In Nepal, Western knowledge in higher education was introduced from the West as part of modern development with international support (Rist, 2014). Such a system tends to marginalize Indigenous and non-Western knowledge, ignoring aspects such as spirituality, empathy, emotions, values, aesthetics, and ethics (Rai & Gaire, 2021).

In Nepal, curricula in higher education are centrally developed and legitimize Western knowledge, which often ignores Indigenous knowledge and local cultural insights (Rai & Gaire, 2021). Indigenous knowledge and ways of teaching, rooted in lived

experiences and continuous interaction and engagement with the environment and the local ideas, beliefs, values and norms passed down through generations, is primarily neglected in higher education curricula (Akullo et al., 2007). The perpetuating Western dominance has devalued lived experience knowledge embedded in the local culture and environment, community practices, institutions and rituals and promoted irrelevant knowledge that is less usable in students' everyday lives. Such decontextualized curriculum practices have not only detached students from their native cultural worlds but promoted the memorization of abstract Western ideas and concepts (Rai & Gaire, 2021).

Nepal was never colonized in the geopolitical sense; however, the nation's academic system has been significantly influenced through colonizing the minds of the elites. Intellectual colonization has implanted a perception of Western superiority, imitating Western thinking methods in an educational environment. As described by (L. T. Smith, 2021), education, similar to research in the context of Nepal, has been a tool for regulating and realizing the colonial agenda, whose rules are rooted in Western scholarly disciplines and scientific paradigms.

My schooling exposed me to layers of colonization, and through my education, I was carrying the colonial baggage in the name of being educated. I migrated to Canada to have a North American degree. Before, I never realized how the education system is designed to undermine Indigenous and non-Western cultures, value systems and appearance (L. T. Smith, 2021). Despite my educational training always pushing me towards emphasizing scientific principles and measurable methodologies, my connections to my family, society, and culture helped me to acknowledge my innate sense of knowing, inner consciousness and spiritual

components. This was an important foundation for working with Indigenous communities and knowledges in my research.

3.1.1.2 Expanding My Worldview with Indigenous Worldviews

In my doctoral journey, while working closely with Indigenous communities, their worldviews have significantly influenced and expanded my own. In the following sections, I will describe Indigenous worldviews and their application through an Indigenous Research Paradigm in my research. I will delve into Indigenous ontology, epistemology, axiology, and methodology, reflecting on how these elements are embedded in my study.

3.1.2 Indigenous Worldviews

Indigenous people around the globe share a similar worldview, which emerged due to their close relationships with the environment (McKenzie & Morrissette, 2003). In Indigenous worldviews, knowledge is holistic, cyclical, and dependent upon relationships and connections to living and non-living entities. Multiple truths exist, formed by individual experiences, and all things are considered alive and equal. Land is considered sacred, the relationship between humans and the spiritual world is predominately significant, and human beings are the least important in the world (L. Simpson, 2000).

Indigenous worldviews emphasize a collective perspective over individualism, focusing on all life forms and their interdependence upon each other for survival, which is often referred to as a relational worldview. The life force is supposed to originate from an unseen yet knowable spiritual realm. Within this worldview, all life forms are connected, and

human beings are neither superior nor inferior to others in the circle of life (J. S. Y. Henderson, 2000). Steinhauer (2002a) further details the teachings that even though we bear responsibility for ourselves, we must never think of ourselves in isolation. Every action and decision somehow affects family, community and the environment around us, a core tenet of the relational worldview. Wilson (2001) further emphasize the relational responsibilities of the researcher to include reciprocity, interdependence, and interrelatedness between individuals in research methodologies.

While reflecting upon the worldviews I have learned through my family, community, religious and cultural practices, education, and personal and professional experiences, it becomes apparent that the Western worldview differs profoundly from the Eastern and Indigenous worldviews. As my current research is informed by the Indigenous worldviews and conducted using Indigenous methodology, my personal worldviews, influence of Western worldviews and Indigenous worldviews, all three have a prominent impression and influence over my worldviews and personality.

3.2 Indigenous Research Methodologies

Indigenous Research methodology is “research by and for Indigenous Peoples, using techniques and methods drawn from the tradition and of those people” (Evans et al., 2009, p.4). In the past and continuing today, many Western researchers researching Indigenous people used a positivistic, reductionist and objectivist method where the research rationale was irrelevant to the community and was informed by colonial ideologies that are exploitative, marginalizing and harmful to Indigenous people (Evans et al., 2009; Koster et

al., 2012). In contrast, the use of Indigenous research methodologies acknowledges the colonial past of Indigenous people, resists colonial narratives, supports the resurgence of Indigenous ways of knowing and being, uses an insider/outsider approach, prevents research extraction, promotes Indigenous self-determination, and combats power dynamics in “traditional research practices” (Chilisa, 2019; Kovach, 2021; L. T. Smith, 2021).

The foundation of Indigenous research is based on the Indigenous ways of thinking that fit within the traditions and culture (Sage, 2017). Indigenous research benefits community people and future generations by preserving and strengthening their tribal identity, stories and narratives (Kovach, 2021). Over the years, Indigenous scholars and graduate students have taken responsibility for preserving traditional knowledge, teachings, stories, ceremonies and philosophies in academia. In the meantime, researchers are working with communities to document such knowledge for future generations (Sage, 2017). On this note, Kovach (2021) states, “Indigenous researchers are finding ways to apply their tribal epistemology into their research work” (p. 25).

Indigenous methods are rooted in Indigenous worldviews and philosophies that promote Indigenous-based ethics and principles in the research process (Weber-Pillwax, 1999; Wilson, 2003). These principles and ethics of Indigenous people set them apart from Western research. Indigenous ontology and epistemology are relational, meaning that relationships form reality (Wilson, 2008). The shared aspect of Indigenous methodology and axiology is that research must maintain accountability for all the relationships that it forms.

3.2.1 Indigenous Research Paradigm

The underpinnings of Indigenous paradigms are based on worldviews that align with Indigenous culture and research outcomes that are respectful and beneficial to the community. Despite rejecting the existing research practices, Indigenous research paradigms provide an alternative way of conducting respectful, protective, appropriate and beneficial research to the community to acknowledge the impact of colonization and resist colonial narratives. While used within the discourse of Western research, the Indigenous paradigm has the potential to generate authentic research outcomes (Koster et al., 2012; Kovach, 2019).

There is no single Indigenous research paradigm, as ways of perceiving and sharing Indigenous knowledge are context-specific (Koster et al., 2012). However, some of the underlying principles are common to all Indigenous paradigms. These principles include recognizing that there exist multiple ways of conducting research, that research objectives should be sympathetic, respectful and ethical to the community, and that Indigenous research should incorporate and be informed by Indigenous perspectives (Louis, 2007). Louis (2007) argues the necessity to identify and adopt Indigenous research methodologies, and (Steinhauer, 2002a) calls for researcher “to reframe, reclaim and rename” (p. 70) the research process. This empowers Indigenous people to take control of their lives, land and cultural identities, frees their voices from the shadows, focus on their issues by respecting their cultural practices and traditions and acknowledges Indigenous realities as an expression of their existence and resilience (Louis, 2007; Steinhauer, 2002b). To support Indigenous research methodology, (Louis, 2007) suggests four concepts- “relational accountability, respectful representation, reciprocal appropriation, and rights and regulations” (p. 133) that

are common discussion related to Indigenous paradigms (Koster et al., 2012; Louis, 2007). Moreover, Johnston et al. (2018), states that Indigenous research is committed to acknowledging and supporting the diversity, nationhood and intellectual self-determination within communities. It recognizes both traditional and contemporary Indigenous knowledge, values community leadership and support, emphasizes community ownership of knowledge and has the potential to regenerate and revitalize the lives of Indigenous people and communities, along with the knowledge that sustains their ongoing well-being.

I used Wilson's Indigenous Research Paradigm (2001) to shape this research and illustrated how a non-Indigenous person conducted Indigenous research. Wilson (2001) stated that a "research paradigm is a set of beliefs about the world and about gaining knowledge that goes together to guide your actions as to how you are going to go about doing your research" (p. 175). Wilson focused on the four aspects of ontology, epistemology, methodology and axiology. I will discuss these four aspects within the Indigenous content and then move forward with how these apply in my research context. According to Wilson, a researcher must reflect on these aspects while writing about research paradigms. Wilson describes ontology as what one believes is true; epistemology as how one thinks about reality. Methodology is how one uses their ways of thinking to gain more about reality and axiology addresses one's morals or ethics (Wilson, 2001).

As an individual with diverse worldviews, the understanding of these ontological, epistemological, methodological and axiological aspects in Indigenous context has helped align my research with the values and ethics of Indigenous worldviews. I will provide a brief detail on these aspects in the section below.

3.2.1.1 Ontology

The Indigenous research paradigm is based upon its ontology, which shapes how Indigenous communities perceive the world. The perception towards the world will influence their understanding of the nature of existence (Hart, 2010). Indigenous worldviews acknowledge multiple realities across communities and nations and understand that perspectives may intersect, diverge or have indirect connections.

(Wilson, 2008) states, “Ontology is the theory of the nature of existence or the nature of reality” (p. 33). From the Indigenous perspective, Earth is considered a Mother, where different life forms are interdependent, such as animals, plants and humans who provide sustenance for life and balance in an ecosystem (Sage, 2017). Indigenous ontology emphasizes that the nature of existence is relational and interdependent and recognizes the interconnectedness of the spiritual realm with the physical realm (Hart, 2010).

The aspects of Indigenous ontology are vague, and describing the whole of Indigenous ontology is beyond my knowledge and capacity; thus, in this section, I am describing the ontological aspect of the Indigenous paradigm that I used in my research process. Although I am non-Indigenous, I know the interrelationship between the spiritual and physical realms through my worldview. I acknowledge and understand the meaning of Mother Earth as in my culture; we treat Earth as a Mother as it provides us food, shelter, air and everything else to sustain our lives. I learned from my worldview that every individual is made up of five elements: water, fire, Earth, space/ether, and this is the main source of our existence. These five elements shape our existence, and when we pass away, we will return

to the same elements. My ways of communicating and maintaining a relationship between the spiritual and physical realm are through prayers, mantras, songs, ceremonies, rituals and festivals similar to Indigenous ontology.

Indigenous ontology is about the relationship one has with the truth (Wilson, 2008). Thus, one's relationship with things or objects is more significant than the object itself. Indigenous ontology puts relationships or sets of relationships higher than anything else. For me, my research didn't only mean recruiting participants, collecting data, analyzing and writing the thesis as I used to do earlier. Rather, when informed and guided by Indigenous ontology, my research required my forming relationships to the knowledge and to the rest of the cosmos which are interdependent. During this research, I considered and reflected on my relationship with self, with family, with people who guided me in this research, my community partner, Elder, supervisors, research participants, with my ancestors, to the land where I come from, to the land where I am living and to the land where I am conducting my research.

Rather than focusing on acquiring knowledge, Indigenous ontology emphasizes forming true relationships with information for it to become true knowledge (Sage, 2017). During the research process, rather than focusing on just obtaining the information, my focus was obtaining knowledge following the principles of respect and reciprocity. Absolon (2022) mentions that it is not just people whom researchers must respect but to honour the natural laws that govern the way we relate with all of Creation. Being a novice researcher in Indigenous methods, I may not have followed all of the principles as Indigenous researchers do. Based on the learning from my worldviews and Indigenous worldviews, I aim to conduct

this research with respect and reciprocity towards the source of knowledge and natural laws that govern our connection with all aspects of Creation.

Reciprocity is the belief that we must also offer to others as we receive from others (Hart, 2010). Reciprocity reflects the significance of relationships and the understanding that we must honour our relationships with other life. Though we differ, all life on Mother Earth is equal, and we should respect all forms of life and be in reciprocal relationships with each other. As truth, relationships, respect and reciprocity are dominant aspects of Indigenous ontology and Indigenous research paradigm, I tried to reflect and align my research with these critical aspects.

3.2.1.2 Epistemology

The Indigenous research paradigm has an epistemology. Indigenous epistemology is the Indigenous way of studying the nature of knowledge and truth (Chilisa, 2019). As Hart (2010) described, “Indigenous epistemology is a fluid way of knowing derived from teachings transmitted from generation to generation by storytelling, where each story is alive with the nuances of the storyteller”(p. 8). Indigenous philosophy is based on the principle that those seeking knowledge are aware and prepared to use such knowledge (Garrouette, 2003). Considered sacred ancestral knowledge, Indigenous traditional knowledge can only be acquired through respect and adherence to strict protocols. Community people are responsible for promoting, protecting and preserving the shared knowledge to be transferred to next generations through ceremonies, storytelling and languages. This shared knowledge has the potential to create modern knowledge. Instead of people seeking knowledge, this

knowledge comes through a dream and/or vision and is intuitive and introspective (Sage, 2017).

Indigenous epistemology has systems of knowledge that have emerged through the interconnections between humans, the spirit and inanimate entities (Hart, 2010), and the relationship between things matters more than the things themselves (Wilson, 2008). Rather than just a way of knowing, Indigenous epistemology is about recognizing an entire system of knowledge and relationships. These are interpersonal, intrapersonal, environmental and spiritual relationships with the cosmos and everything in this cosmos. Indigenous epistemology is Indigenous peoples' culture, worldviews, times, languages, histories, spiritualities and places in the cosmos (Wilson, 2008). Hart (2010) further mentions that the Indigenous research paradigm is structured around epistemology grounded in a subjective process for knowledge generation while relying on Elders and individuals who possess such insight.

Indigenous epistemology is experienced by exercising inwardness rather than by looking out at the world (Ermine, 1995). Through internal exploration, individuals access the creative forces that run through all life, realizing the subjective experience of the wholeness of the universe and Indigenous knowledge. The rituals, ceremonies, dreams, vision, meditation and prayers facilitate one to connect with the things happening around them. Thus, in Indigenous cultures, the spiritual realm holds a higher place, which helps discover the inner space, a perceptual experience. Elders are the ones who have dedicated themselves to practicing and developing this ability and take up important roles in Indigenous

communities. In Indigenous epistemology, knowledge is developed through the subjective process, and communities rely upon Elders who have developed such insight (Hart, 2010).

Marquez (2022) mentioned that when non-Indigenous researchers engage with Indigenous knowledge, they should explicitly acknowledge that their epistemology is borrowed and informed by Indigenous knowledge rather than claiming ownership over the knowledge. As a non-Indigenous person, I cannot claim that I gained Indigenous knowledge and understood the truth by reading Indigenous epistemology and conducting Indigenous health research. However, I tried to observe and follow the protocols used in Indigenous research methodologies as per my understanding. Indigenous knowledge is built upon relationships between things; during the research process, my relationship with the partner organization, my supervisor, Elders, mentors and research participants were of higher importance to me than the research outcomes. I often reflected upon my work through prayers, meditations and rituals. I participated in the Indigenous practices of smudging, starting my research project with Elders' opening and closing prayers, having Elders in my Community Advisory Group, offering tobacco to the Elders, receiving the blessing of Elders from communities, and closing my research process with a feast and gifts/honorarium.

3.2.1.3 Axiology

Axiology is the fourth aspect to discuss in the Indigenous research paradigm. Axiology is a branch of philosophy that explores the nature of morals, values, ethics, obligation, justification, and virtue (Wilson, 2008). Research is not only a process of acquiring knowledge but also a process of forming a relationship between researcher,

research, research participants and the knowledge gained. The researcher has the responsibility and accountability to impart the knowledge respectfully and strengthen the relationship formed during the research process. During the process of conducting the research, researchers should follow ethical conduct guidelines to maintain accountability.

Researchers should understand and acknowledge the significant traditional and cultural protocols while acquiring Indigenous knowledge. For instance, in Anishinaabe communities, tobacco is offered to the Elder before initiating the research process. Offering tobacco is a way of building relationships with people and acknowledging trust (Sage, 2017). In my research process, I talked about how I followed the protocols and values of my partner organization and how this dissertation honoured the protocols and responsibility for assuring that knowledge was shared according to the community members' instructions.

There are several values, principles, ethics, and protocols across diverse Indigenous communities. Hart (2010) has identified some principles and values for Indigenous research. These values include Indigenous control over every possible stage of research; respect for participants and communities; reciprocity and responsibility of researcher by sharing and presenting ideas to support the community; safety and confidentiality of research participants; non-intrusive observation; emotional and spiritual involvement in research by deep listening and hearing; reflective non-judgement; honouring the participant's voice; involvement of mind and heart; and, self-awareness and subjectivity of the researcher in the research process. In accordance with the description above, during my research process my community partner had control over all the stages of research and I followed the protocol outlined by my community partner, Maamwesying North Shore Health Services.

Maamwesying team members were involved in the research planning process, presenting research objectives and motivation to the potential participants, recruitment of participants, supported me in data collection, and reimbursed the participants for their time as an appreciation. I shared my results with Maamwesying and community advisory group, and my community partner and I presented the research approach and methods at an international conference.

On the values of researchers, Weber-Pillwax (2001) mentioned that research should align to the needs of the community and benefit them. She beautifully reflected on the importance of the researcher's integrity as a person and a human being. Personal integrity is based on how a researcher contextualizes themselves as an individual and part of family, community and the universe.

The aim and motivation of my research aligned with the interests of Maamwesying, who is embarking on efforts to provide culturally appropriate and relevant comprehensive dementia assessment and care services through community-based memory clinics in the Anishinaabe communities they serve. They embraced me and supported me throughout my research journey. My intention in conducting this research was to contribute towards the benefit of community-based care for older people, to learn, and to complete the requirements of my degree. While building a relationship with the community partner, my personal worldviews and Indigenous worldviews that I studied helped me to understand my identity as an individual and a part of the cosmos. After I started learning about Indigenous ways of knowing and being, I began to realize the importance of acknowledging my identity and my relationship to the place of my origin and current residence. It made me more accountable to

the people with whom I am working. I presented my research objectives, motivation and potential community benefits of my research to the Senior Patient Advisory Group, a group of older Anishinaabek who come together to guide the activities and services of Maamwesying. They blessed my research and granted me permission to proceed. This process was crucial as Maamwesying always consults with their Senior Patient Advisory Group before making any decisions for their communities.

3.2.1.4 Methodology

Out of this Indigenous research paradigm, emerges Indigenous research methodologies. Indigenous methodologies emanate from an Indigenous ontology and epistemology grounded upon relationships. As per (Weber-Pillwax, 1999), Indigenous methodologies allow Indigenous researchers to be their original selves in the research process. Besides creating new knowledge, Indigenous methodologies empower a researcher's Indigenous identity and positionality (Weber-Pillwax, 1999). Wilson (2008) emphasizes that Indigenous methodology should follow 'relational accountability,' which means "the methodology needs to be based in a community context (be relational) and has to demonstrate respect, reciprocity and responsibility (be accountable as it is put into action)" (p. 99). Researchers are responsible for fulfilling their relationship with the world around them (Kovach, 2021; L. T. Smith, 2021; Wilson, 2008). Wilson (2008) states that "relational accountability" concerns the researcher fulfilling and answering all relations while conducting research. Thus, he emphasizes, rather than answering questions of reliability and validity of the research, researchers should ask themselves whether they are fulfilling their

role in the relationships. A researcher has a relation not just with the research subject but with the cosmos, plants and animals and the earth as a whole, and the researcher should be aware of these relations all the time. Indigenous methodology is not only about gaining knowledge but also about using the knowledge gained practically and in an appropriate way that benefits the community and its people.

Indigenous research methodologies reflect how knowledge is understood and sought in the context of the worldviews, ontologies, and epistemologies of diverse Indigenous nations (Johnston et al., 2018). Indigenous research methodology honours ancestors through oral histories by maintaining the validity of their stories in the contemporary world. Bagele Chilisa (2019), born in the country of Botswana in Southern Africa, describes the Indigenous Research Paradigm as a postcolonial Indigenous research paradigm that is “a framework of belief systems that emanate from the lived experiences, values and history of those belittled and marginalized by the Euro-Western research paradigms” (p. 19).

Thus, Indigenous methodologies are coherent and consistent with Indigenous values and worldviews and ensure the relational accountability of Indigenous research, which implies respect, collaboration, reciprocity and researcher reflexivity (Kovach, 2021; Wilson, 2008). In practice, Indigenous methodologies are coherent, culturally relevant, and support the self-determination of Indigenous peoples (L. T. Smith, 2021). Relationality could be addressed using Indigenous methodologies following the 4Rs principles: respect, relevance, reciprocity and responsibility.

Being a non-Indigenous researcher, my values and worldviews are not grounded in Indigenous worldviews, and in some ways differ from Indigenous epistemology and

ontology. However, in a conversation with Dawn Marsden, Absolon (2008) stated that “non-Indigenous people can adopt Indigenous methodologies if they’re doing it in a good way, in good relationships with the people they’re doing it with and with full recognition, acknowledgment of the genealogy of that knowledge” (p. 264). Guided by my supervisors and committee members, I have tried my best to conduct this thesis research in a good way, forming good relationships with my community partner, community advisory group, Elder, Senior Patient Advisory Group, research participants and other people who supported me. I fully recognized their contributions and acknowledged their knowledge.

3.3 Selecting a Research Topic

Following Wilson’s Indigenous Research Paradigm (2008), it is important to provide details on how the research topic was selected as it makes researchers accountable to their relation towards the research and research participants. This section will describe my introduction to the research, my evolving perception about Indigenous research, the selection of functional assessment in dementia as the research topic, and the rationale for selecting a scoping review and focus group to lay the groundwork for developing Indigenous functional assessment tool.

Indigenous research from the Western worldview often highlights the negative aspects and challenges within the community and its people. Reflecting on my experiences as a public health personnel back home in Nepal, I was trained in Western research methodologies. Thus, while working on various health-related concerns, I presented the health concern primarily from negative connotations. I remember constantly focusing on the

statistics on the prevalence and incidence of HIV and AIDS, uterine prolapse in rural women, respiratory disease from indoor air pollution, child and maternal mortality, food insecurity and more. In countries like Nepal, research priorities and interventions are primarily determined by the preference of donor agencies from the Western world rather than the community's real needs. Government and community organizations overlook the community's strengths and illustrate the community's problematic image to secure funding. However, before initiating any intervention, it is necessary to understand and acknowledge the social, cultural, historical and economic context while designing the interventions with communities rather than directing solutions.

For years, in Nepal, I focused on researching and identifying the negatives and weaknesses of communities rather than emphasizing the positive aspects, which contributed to alienation and lack of relationship with the community. My role as a researcher and program coordinator was more dominant in the project than that of community and determining what needs to be done within the community. However, my perspective shifted when I chose a research project for adapting the *Kimberley Indigenous Cognitive Assessment (KICA)* (LoGiudice et al., 2006a) for dementia assessment in Nepal for my Ph.D. Initially, I did not consult with the communities before choosing a topic but later engaged with stakeholders from various communities, discussing the research objective and establishing partnerships. However, due to the COVID-19 pandemic in 2020, I could not travel to Nepal from Canada for data collection and had to shift my research topic.

During the early days of my Ph.D., I enrolled in an Indigenous health class, interacted with Elders for my class preparation, participated in activities such as blanket exercise and

smudging ceremonies, watched documentaries focusing on residential schools and the oppression faced by Indigenous Peoples, attended conferences on webinars on Indigenous health and studied Truth and Reconciliation reports. These experiences gave me a deeper understanding of Indigenous Peoples' historical, social, cultural and political context in Canada, the USA, Australia and Aotearoa/New Zealand.

Due to the uncertainty of the pandemic, I decided to change my research topic following the suggestions of my supervisors and faculties. However, I doubted myself and questioned whether, as a non-Indigenous individual, I should engage in research with Indigenous communities. I reflected on the journey I had undertaken. I realized it was an opportunity to learn and acquire knowledge in conducting research in a culturally sensitive and respectful manner with Indigenous communities. I perceived it as an avenue to redefine my relations with the land I now call home and the individuals I encounter daily. The scope of my relationship has extended beyond my immediate family, community and nation to encompass a global context through my work.

With the discussions with my supervisor, I aimed to adapt a functional aspect of the *Kimberley Indigenous Cognitive Assessment (KICA)* tool in the First Nations context in Canada. The adaptation of the functional assessment tool was supposed to complement the Canadian Indigenous Cognitive Assessment, a tool adapted and validated by Dr. Kristen Jacklin and Dr. Jennifer Walker in partnership with the First Nations communities in Manitoulin Island (Jacklin et al., 2020a; Walker et al., 2020) . The need for this research

topic was identified by the Community Advisory Group and the physicians involved in the validation of *CICA*. After identifying the research topic, I consulted with Indigenous and non-Indigenous researchers and academicians working in dementia and Indigenous populations for a long time. They advised me to develop a functional assessment tool in the context of the Indigenous Peoples of Canada. Also, they suggested I conduct a review to identify the methods and approaches relevant to developing health assessment tools in the Indigenous context. I presented my revised research topic with my Supervisory Committee, Laurentian University Graduate Symposium, and the Canadian Consortium on Neurodegeneration in Aging (CCNA) conferences. The feedback and insights from this platform helped me refine my research topic of laying a groundwork for developing an Indigenous Functional Assessment in the First Nation context. The details of the study are provided in the following sections.

3.4 Research Methods

As noted in Chapter 1, the research objectives of this study were 1) to identify the existing literature on the approaches and methods that have been used to adapt and develop health assessment tools used for Indigenous populations across Canada, the United States, Australia and Aotearoa/New Zealand and 2) to conduct preliminary community-based research to inform the development of an Indigenous Functional Assessment tool, based on the learnings from the literature. A Community Advisory Group (CAG) was formed to guide this study. To meet the research objectives, this study was conducted in two phases. Firstly, a

scoping review was conducted to identify literature on Indigenous research methods and approaches used in health assessment tools. Secondly, a qualitative design incorporating a participatory research approach, including focus groups with health professionals was conducted.

As the 5th CCCDTD recommends, primary care health professionals are able to diagnose most of dementia in Canada (Ismail et al., 2020), various health care professionals are involved in assessing dementia across Canada. Thus, I conducted two focus groups with Indigenous and non-Indigenous health professionals who were involved in assessing cognitive and functional decline in Indigenous communities. I aimed to understand their perspectives on the aspects of functional impact due to cognitive decline that are important to include in an informant tool for assessing function, especially Instrumental Activities of Daily Living (IADLs). Both of these methods aligned well with the theoretical and methodological framing of this research and have been used successfully for collecting rich and contextualized data in the context of Indigenous health research. The details of methods of conducting both the scoping review and focus groups are described in the section below.

3.4.1 First Phase- Scoping Review

My early meetings with scholars and researchers across Canada working in the field of Indigenous health and cognitive assessment suggested conducting a literature review to identify the relevant approaches and methods necessary to develop a functional assessment tool that is culturally grounded, appropriate, relevant and safe to use in an Indigenous

context. The findings from the scoping review helped to inform the approaches and methods for the later part of my study.

3.4.1.1 Scoping Review Objectives

This scoping review aimed to identify approaches and methods used to inform the adaptation or development of health assessment tools used for Indigenous populations across Australia, Aotearoa/New Zealand, Canada, and the United States. We identified the approaches used in health assessment tool development based on Indigenous perspectives and worldviews. We intended to inform Indigenous Peoples, nations, networks, groups, communities, research institutions and researchers involved in conducting Indigenous health research about the possible approaches and methodologies being used in Indigenous research that could be translated into policies and programs designed to achieve the overall health of Indigenous people.

3.4.1.2 Scoping Review Research Question

1. What approaches and methods are used to inform the adaptation or development of health assessment tools used for Indigenous populations across Australia, Aotearoa/New Zealand, Canada, and the United States?

The research question was developed based on discussions with Indigenous health researchers and clinicians working with the Indigenous cognitive assessment in Canada, who

mentioned the paucity of research that looked into approaches and methodology used to develop the health assessment tool specifically for the Indigenous population.

3.4.1.3 Scoping Review Framework

Our review was guided by the Indigenous Wholistic Framework, originally developed by Pidgeon in 2008 and later refined (Pidgeon, 2016). This framework is the pictorial representation of Indigenous wholism that represents the interconnectedness of the physical, intellectual, spiritual and emotional realms and the inter-relatedness of these realms to individuals, family and community and the surroundings, such as land and water (shown in Figure 1). Further, it encompasses the 4Rs of respect for Indigenous knowledge, responsibility (i.e., responsible relationships), relevance, and reciprocity developed by Kirkness & Barnhardt (1991) to guide post-secondary institutions to support Indigenous students. It recognizes that one's physical needs are linked to the spiritual, intellectual, and emotional dimensions and that living a balanced life is about meeting each of these sustained by one's inter-relationships.

This framework guides researchers to reflect on their relationship with the research, their identity as an Indigenous or non-Indigenous person in a relationship to the people and geography where the research is taking place, and their centring of Indigenous ways of knowing and being throughout the entire process. This framework guides how the tool adaptation and development process followed the principles of respect, relevance, responsibility, and reciprocity from the emergence of research, its design, data collection, analysis and dissemination.



Figure 1 Indigenous Wholistic Framework (Pidgeon, 2016)

The concepts related to 4R are difficult to interpret in isolation as each of the concepts are interrelated and complement each other; however, I tried to conceptualize the 4R in the articles used in the study. Below, I provide a short description of what respect, relevance, responsibility and reciprocity meant in our study.

3.4.1.3.1 Respect

Respect stands for acknowledging Indigenous knowledges, worldviews, and beliefs (Kirkness & Barnhardt, 1991). Research grounded in Indigenous epistemologies and

methodologies ensures that Indigenous voices are heard and guides the research process (Denzin et al., 2008; L. T. Smith, 2021). While conducting Indigenous research, researchers are meant to respect and acknowledge the territory and traditions within which they work (Pidgeon, 2019). An Indigenous framework is used in the research process to guide the work. Indigenous methodologies set a decolonization context, and include cultural processes, such as Medicine Wheel teachings or yarning, and may also include relevant methods such as photo voice. The formation of a community advisory group or an Indigenous reference group provides guidance about the appropriate community protocols and processes. In some cases, a community has their own research ethics board besides the university's research ethics board and researchers must follow their process. Researchers who respect the Indigenous research process must consider the Indigenous knowledge in a reflective and non-judgmental way that is being seen and heard.

3.4.1.3.2 Relevance

Relevance refers to the value and meaningfulness of a research project to the Indigenous Peoples and communities, Indigenous worldviews, and their way of living and knowing (Kovach, 2021). While conducting a study, researchers should consider the historical and contemporary understandings of Indigenous realities and relationships (Pidgeon & Riley, 2021). This means the research must be pertinent to the issues and concerns of the population being studied, which moves research beyond securing funding, approval, or addressing the gap, in theory, to ensuring the utility of findings to participating communities. Adapting or developing the health assessment tool in the context of Indigenous

communities needs to be relevant to and sanctioned by the communities, reflecting their needs and competencies (McCubbin & Moniz, 2015).

Relevance also means understanding and being aware of the socio-ecological context of communities, as Indigenous communities are culturally diverse, and the "one-size fits all" approach is not applicable across communities. Similarly, Indigenous research should empower the communities (L. T. Smith, 2021) by building research capacity, which enhances self-determination (Pidgeon & Riley, 2021).

3.4.1.3.3 Responsibility

The researcher is responsible for continually seeking to develop and sustain a credible relationship with communities. The researcher is responsible for protecting the community and the participants from any risk occurring from the beginning until the end of the study, addressing the community's expectations and needs related to the research and the researchers. Researchers uphold ethical responsibility to ensure that Indigenous data and knowledge are shared ethically and in culturally appropriate ways that enhance sovereignty and self-determination (McCubbin & Moniz, 2015; Pidgeon, 2019). Moreover, the researcher is responsible for engaging with the community appropriately, and being conscious of his or her biases and impact of intention and motive on the community (Pidgeon, 2019). A researcher's responsibilities are to ensure the community has access to information and data at various stages of the research, that their voice is ensured in disseminating the findings, and that they are able to use the results to enable and/or urge reparation for their community and its citizens. Responsibility also means following the principles of Ownership, Control,

Access and Possession (OCAP®) of the data. Researchers should address issues such as the ownership of data, possession of data by whom, dissemination of research, findings, and impact of those findings on the community (McCubbin & Moniz, 2015).

3.4.1.3.4 Reciprocity

Reciprocity means not only disseminating the study results but also entitling knowledge holders as the source of knowledge (Hart, 2010; Kovach, 2021; L. T. Smith, 2021). The knowledge obtained from the research not only contributes to the local people's future well-being but also to tangible community benefits while the researcher is among them (Paksi & Kivinen, 2021). Reciprocity highlights research as part of gift exchange, including the gift of skills, knowledge, and experience (Pidgeon & Riley, 2021). Reciprocity is grounded in the traditional values of Indigenous Peoples, allowing for continued commitment to traditional values and respecting self-identification. Shared learning and capacity building are essential forms of providing community members the opportunity to be trained in research. At the same time, researchers can also gain knowledge about local history, practices, values, and knowledge systems. Furthermore, reciprocity is reflected by tangible activities such as hiring community people as staff in a research project, recognizing the community member or community in the research project, sharing the research results with the community, and adjusting the research design to fit particular community needs and priorities.

3.4.1.4 Scoping Review Methods

3.4.1.4.1 Protocol and Registration

The protocol was drafted using the latest 2020 Joanna Briggs Institute (JBI) methodology for scoping reviews. The scoping review protocol was registered prospectively with the Open Science Framework database (<https://osf.io/yznwk>) and has been published in the BioMed Central Systematic Review (Sharma et al., 2024).

3.4.1.4.2 Eligibility Criteria

3.4.1.4.2.1 Participants

The scoping review included studies that focused on Indigenous populations. “Indigenous” referred to the original peoples of Australia, Aotearoa/New Zealand, Canada, and the United States. Indigenous people in these countries are identified with different names and identities such as Indigenous, Aboriginal, Native, Indian, Native American, First Nation, Métis, Inuit, Māori, Torres Strait Islander and many more. There are many other Indigenous people worldwide, but we focused on Indigenous people within these four countries as they experience a similar history of colonization and its detrimental effects on their health and well-being (Kovach, 2021; Morton Ninomiya et al., 2017; L. T. Smith, 2021). The review included studies that focused on Indigenous people of any age, gender, and sex.

3.4.1.4.2.2 Concept

This review included studies that describe the development of new health assessment tools for use with Indigenous populations or the adaptation of existing mainstream health assessment tools. I primarily focused on identifying the methods and approaches used while developing or adapting the tool for use, particularly in Indigenous health assessment. Health assessment tools that assess health status, health conditions, human development (e.g., cognitive or physical) or quality of life were included.

3.4.1.4.2.3 Context

This scoping review included studies from Australia, Aotearoa/New Zealand, Canada, and the United States. There are distinct groups of Indigenous people living across these countries, and I included studies involving diverse Indigenous groups and communities. The detailed eligibility criteria are found in Table 2.

3.4.1.4.3 Information Sources

To identify potentially relevant documents, the following bibliographic databases were searched from January 1st, 2000, to October 31st, 2021: PubMed, APA PsycINFO, CINAHL, Medline, Web of Science, Bibliography of Native North Americans, Australian Indigenous Health info data set, and Indigenous Health Portal of University of Saskatchewan. I drafted the search strategies with the help of an experienced librarian and further refined them through discussion with the thesis supervisory committee. Peer-reviewed journal papers were included if they were: published between January 1st, 2000, to

October 30th, 2021, written in English, and where the paper produced a health assessment tool as the outcome of the research. Qualitative, quantitative and mixed-method studies were included in order to consider the process of adaptation or development of an instrument. Dissertations, thesis, and articles that did not produce a health assessment tool were excluded. The paper focused on Indigenous populations in Australia, Aotearoa/New Zealand, Canada, and the United States were included in the study.

3.4.1.4.4 Search

An initial limited search of PubMed and APA Psych Info was undertaken to identify articles on the topic. The words contained in the titles, abstracts, and index terms of relevant articles were used to develop a full search strategy for PubMed (Table 1). The final search strategy for all database and grey literatures is found in Appendix I.

Table 1 Pubmed Literature Search Strategy

1.	<p>((("Indigenous Canadians"[Mesh] OR "Indigenous Peoples"[Mesh] OR "Indians, North American"[Mesh] OR "American Natives"[Mesh]) OR ("Oceanic Ancestry Group"[Mesh]))</p> <p>OR</p>
2.	<p>(Indigen*[tiab] OR Aborig*[tiab] OR Torres Strait Islander*[tiab] OR Indigenous[tiab] OR Aboriginal[tiab] OR Indian, North American[tiab] OR Alaskan Natives[tiab] OR Native Hawaiian[tiab] OR First Nations[tiab] OR Metis[tiab] OR Inuit[tiab] OR Maori[tiab] OR Australian Aboriginal[tiab]))</p> <p>AND</p>
3.	<p>(adapt*[tiab] OR develop*[tiab]) AND ("assessment tools"[tiab] OR "screening tools"[tiab] OR "diagnostic tools"[tiab] OR tool[tiab] OR measure[tiab] OR instrument[tiab] OR question*[tiab])</p> <p>NOT</p>
4.	<p>("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review")</p>

Table 2 Eligibility Criteria

Inclusion criteria	Exclusion criteria
<p>English-language articles</p> <p>Published in between Jan 1, 2000, to October 31, 2021</p> <p>Peer-reviewed journals</p> <p>Grey literatures</p> <p>Indigenous Peoples of Canada, the United States, Australia and Aotearoa/New Zealand</p> <p>Indigenous People of any age, gender and sex</p> <p>Outcome of selected study should be adaptation of existing mainstream health assessment tools or development of new health assessment tools for use with Indigenous populations</p>	<p>Any reviews, systematic or critical or narrative reviews</p> <p>Presentations/poster abstracts, protocols, brief reports, editorial letters, guidelines</p> <p>Study on acceptability, reliability and validity of a tool or instrument</p>

3.4.1.4.5 Selection of sources of evidence

The final search results were exported to Zotero (Corporation for Digital Scholarship, 2024) , and I removed duplicates. After the duplicates were removed, the data were extracted

to Rayyan software (Ouzzani et al., 2016). Based on the eligibility criteria, two independent reviewers (i.e., included me and my supervisor's Research Assistant) screened the titles and abstracts in the first stage and the extracted full-text articles were stored in an Excel spreadsheet. Afterwards, full-text articles were screened by the same two independent reviewers. The disagreement on study selection in both stages was resolved by discussion and consensus between the two reviewers.

Additional papers were searched through a hand search looking into the references of full-text articles identifying an additional 12 articles. The additional papers were screened by the two independent reviewers using the eligibility criteria.

3.4.1.4.6 Data Charting Process

Data from eligible studies were charted developing the data items. The developed data items were shared with my supervisor and co-supervisor to determine which variables to extract. I charted the data in Microsoft Excel, discussed the results, and continuously updated the data charting through an iterative process.

3.4.1.4.7 Data Items

The data extraction sheet in Microsoft Excel included basic descriptive information regarding each paper, including the year in chronological order and author names. Additionally, the details were recorded from each paper pertaining to the tool/instrument that was adapted or developed, including the names of the tool/instrument, the measure it assessed, country, the Indigenous population to which it applied, and a summary of the

processes, methods and approaches used in adapting and developing a culturally safe and relevant health assessment tool to be used in an Indigenous context.

3.4.1.4.8 Synthesis of Results

I chronologically charted the studies according to the publication data to see how the Indigenous approaches and methods used in the tool adaptation and development process evolved over time. I used (Pidgeon, 2016) Indigenous Wholistic Framework, which is adapted from (Kirkness & Barnhardt, 1991) 4R of respect, relevance, responsible relationship, and reciprocity to analyze and synthesize our data. The findings of the scoping review are detailed in Chapter 4.

3.4.2 Second Phase- Focus Groups

In this phase, I conducted community-based participatory research (CBPR) in partnership with Maamwesying North Shore Community Health Services. In this section, I will describe integrating CBPR into my project, relationship building, community engagements, participant recruitment, data collection and data analysis.

3.4.2.1 Integrating Community-based Participatory Research (CBPR) into this Project

The second phase of research followed a Community-Based Participatory Research (CBPR) approach that privileged the input from an Indigenous health organization in the design, development, and implementation of the project. In this section, I will describe the

basic attributes of CBPR along with its relation to Indigenous methodologies and how I used CBPR in my research process.

CBPR is a partnership between the researcher and community members where expertise is mutually shared (Israel et al., 1998). It is a collaborative process where researchers and the participants contribute unique strengths and shared responsibilities. Primarily, such a research process helps to develop a more enhanced understanding of the research topic and the cultural dynamics of the community and integrates knowledge and action for the benefit of the community (Israel et al., 1998). Traditionally, research practices used to be conducted where researchers, in a structural position of privilege, exerted more power on the research participants; however, CBPR helps to balance the power imbalance by involving community and community participants in all stages of the research process (Banks et al., 2013). CBPR helps build the capacity of the community by providing a voice to the community.

Israel provided some of the basic principles of CBPR; however, these principles are flexible and continue to evolve with the advancement of research knowledge in the field (Israel et al., 1998). The use of these principles while conducting research depends upon the context, purpose and participants involved in the process. The main goal of CBPR is equitable participation of the research and research participants and shared control over all phases of the research process, from problem identification to application of results in addressing community concerns. CBPR helps identify and build on the strengths, resources and relationships within communities to recognize and address communal health concerns. Community is a substantial part of people's identity and is constructed through social

interactions. Thus, CBPR is conducted with the existing community through collective engagement.

In some cases where community people are not involved, representatives from health service organizations, academia, and community-based organizations are involved in developing such partnerships (Israel et al., 1998). Maamwesying North Shore Community Health Services, an Indigenous community health organization, was involved as a community partner in this research. The foundation of this research is based on the basic principle of CBPR- reciprocity, which is the transfer of knowledge, skills, capacity and influence between researchers and community members. During the research process, both the researcher and the community partner ensured that there was mutual transfer of knowledge, skills, capacity and influence. CBPR is a cyclical and iterative process involving the formation of nurturing partnerships between the researcher and community members, community assessment, problem identification, development of methodology, data collection and analysis, interpretation of data, policy implication and knowledge translation, sustainability of the project and the established relationship (Israel et al., 1998; J. E. Simpson & Mendenhall, 2022). In CBPR, the ownership of knowledge is always acknowledged (Israel et al., 1998). My relationships with the Maamwesying developed over the years, and the research process also evolved with time. The involvement of Maamwesying at various stages of the research process significantly shaped the research methods and design. Through collaborative discussions, we (Maamwesying and I) adapted the project to align with the community priorities, feasibility and resource availability. Initially, we engaged with health directors of different Indigenous health organizations; however, they couldn't contribute due

to limited capacity, despite their interest. Therefore, we revised our approach, actively participating in meetings with primary care health professionals who were directly involved in providing dementia-related care and services. I presented research objectives and community benefits to them both in-person and online. Throughout the recruitment and data collection phases, we continuously evaluated and adjusted our methods as needed. This iterative process involved ongoing discussions, planning, methodological adjustments, community engagement, presentation and incorporating feedback.

Over recent decades, CBPR has gained recognition as a promising approach to understand and tackle various health inequities in Indigenous communities. This approach can potentially transform how research has historically been conducted with Indigenous communities. While conducting CBPR, it is crucial for researchers to consider Indigenous communities' unique social, historical, political, cultural and geographic contexts (Christopher et al., 2011). As a process of understanding the contexts of Indigenous peoples in Canada, I consulted text-books, courses, workshops, and webinars, and engaged with various communities, leaders of Indigenous health organizations, and Elders.

The frameworks used in CBPR complement Indigenous research methodologies in the philosophy of research and approach (Drawson et al., 2017). The CBPR framework ensures commitment to social transformation, honouring the lived experiences of the participants and community, and commitment to power-sharing in research (Evans et al., 2009). Moreover, Indigenous research methodology, along with CBPR approaches, deliberately empower individuals whom traditional research practices have marginalized (Evans et al., 2009). My research utilized a community-based approach, partnering with

Maamwesying, to address power differentials in research, promote shared decision-making and validate mutual ownership of the research. The process involved actively listening to and learning from the community partner and honouring the lived experiences of community and community partner (Viswanathan et al., 2004). Thus, it is an iterative process where the researcher constantly negotiates with the community partner and follows local protocols and research approval mechanisms with the Indigenous authorities.

Indigenous advisory committees, typically consisting of Elders, tribal councils or band councils, are essential to Indigenous methodologies as they represent the communities and their research interest and provide the researchers with knowledge, wisdom and guidance to align research with Indigenous worldviews (S. Flicker et al., 2015). This ensures that the research is relevant, transferable, applicable, and following local protocols that align with community priorities (Marquez, 2022). In addition, the local insights provide rigour and increase the efficiency of time and resources (Tobias et al., 2013). I formed a Community Advisory Group (CAG) consisting of an Elder and a community researcher to guide my research. My research proposal was presented to the Senior Patient Advisory Committee (Senior PAC), a group established by Maamwesying to guide research and programming for older community members. The endorsement and contributions of the Senior PAC guided the Maamwesying to ensure that their engagement with me as a researcher aligned with the priorities of the Anishinaabe communities and seniors that they serve.

Collaboration or partnership with community leaders and communities is essential in community-based research. As Indigenous communities are not homogenous, collaboration with community leaders might not always represent the voices and interests of community

members (Tobias et al., 2013). In such cases, it is necessary to invest time in building trusting relationships. Also, community-based research and Indigenous methodologies are rooted in relationality (Kovach, 2017). Nonetheless, the time invested in forming a relationship with the Indigenous community is imperative. Besides forming a relationship, designing a project collaborating with communities reflects the community's values and priorities. The research process empowers Indigenous communities to determine their ethical codes of conduct for researchers. Some communities have culturally relevant ethical principles and ethics boards to ensure researchers follow the protocols and principles (Marquez, 2022); however, Maamwesying didn't have their own research ethics board.

My research objective was to conduct a preliminary study to inform the development of a functional assessment tool that aligned with the culturally-grounded health services priority of Maamwesying. Thus, my focus was to develop relationships with Maamwesying. In this process, my role was to lay a foundation through research for Maamwesying to carry out the tool development process with ownership, control, as well as further develop and sustain this work. I followed principles for a culturally and community-appropriate approach, which included partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect (Jacklin & Kinoshameg, 2008). These principles aligned with the recommendations for ethical research with Indigenous Peoples outlined by Tri-Council Policy Statement on Ethical Conduct for Research Involving the First Nations, Inuit and Métis Peoples of Canada (CIHR, NSERC, SSHRC, 2010), The Canadian Institute of Health Research (CIHR) Guideline for Health Research Involving Aboriginal Peoples (CIHR, 2013) and the National Aboriginal Health Organization principles of ownership,

control, access and possession (OCAP®). This project was approved by the Laurentian University Research Ethics Board (Approval number: 6021023- Appendix A), which align with the Tri-Council Policy. While Maamwesying does not have its own Research Ethics Board, I tried to follow the protocols mentioned directly or indirectly by Maamwesying during the research process. Alongside this research and other ongoing work, Maamwesying began the process of developing its own community research ethics board.

Although CBPR is a methodology developed in a Western cultural context, its acknowledgement of community requirements provides a transitional methodological process toward Indigenous paradigms (Koster et al., 2012).

3.4.2.2 Relationship Building

My research topic was relatively new; thus, I undertook multiple meetings and discussions with my supervisors and supervisory committee, as well as self-study and reflection on my new research direction. I was fortunate to benefit from my supervisor's pre-existing relationships with communities in Northern Ontario and researchers working in Indigenous communities across Canada. Through her guidance, I contacted the Alzheimer's Society of Sudbury, Manitoulin and North Bay Districts, Noojmowin Teg Health Centre and Maamwesying North Shore Community Health Services in the March and April of 2021. The Alzheimer's Society of Sudbury, Manitoulin Island and North Bay Districts was formerly established in 1983 and provides essential programs and support services to those living with dementia as well as their care partners. The Executive Director of Alzheimer's Society expressed interest in supporting my work during a meeting in April 2021 and provided me

with a support letter. Maamwesying North Shore Community Health Services and Noojmowin Teg Health Centre are two Indigenous health organizations providing quality health services to the Indigenous communities in Manitoulin Island and other communities in Northeast Ontario from Sudbury to Sault Ste. Marie. I met the then-executive director of Noojmowin Teg Health Centre in June of 2021 and Maamwesying's current Director of Home and Community Care Support Services in April 2021. Both organizations showed interest in supporting my work and provided letters of support.

3.4.2.2.1 Establishment of the Community Advisory Group

Establishing a Community Advisory Group (CAG) is an essential phase of conducting Indigenous research. I started building relationships with Noojmowin Teg and Maamwesying through my supervisor's pre-existing relations. I was invited to their monthly research meeting, where they discussed their projects on dementia care in communities across Manitoulin Island, Sudbury and Sault Ste. Marie. I consulted with the team about potential people in my Community Advisory Group to guide my research in following the Indigenous approach and methods. Mariette Sutherland, who worked for more than the past 16 years and completed over 125 Indigenous projects, agreed to be in my CAG to guide me in my research project. She is an Anishnaabe from Whitefish River First Nation, a community in Northeast Ontario and was the former Executive Director for Noojmowin Teg Health Centre. Currently, she is a community engagement resource for the dementia-related project named MIND and WISE care undertaken collaboratively by Maamwesying and Noojmowin Teg in Northeast Ontario. Broadly, she conducts respectful community-based

research and engagement in First Nations and Indigenous health issues, which informs the conceptual design of service models, effective proposal development, planning, evaluation and recommendations.

I was looking for an Elder for my CAG to guide me and my research with Indigenous wisdom and knowledge. M. Sutherland recommended Elder Jean Andrews McGregor to be in my project. Elder Jean has been involved in various projects related to dementia in her communities, including the adaptation and validation of the Canadian Indigenous Cognitive Assessment. She represented Canada on the Elders' Panel at the inaugural conference of the International Indigenous Dementia Research Network in November 2023 in Hawai'i.

Further, the Alzheimer's Society Sudbury-Manitoulin North Bay and Districts were interested in supporting me; thus, the Public Relations and Education Manager, Jessica Bertuzzi who used to coordinate programs at Manitoulin Island, agreed to be in the CAG. I developed the terms of responsibility for CAG, which are attached in the Appendix B. Due to the ongoing COVID-19 pandemic and the restrictions in place, I had my first CAG meeting online on November 30, 2021. I intended to start my research project in an Indigenous way of offering tobacco to the Elder; however, this could not happen, but the meeting started with the opening prayers and smudging and ended with closing prayers. Before the meeting, I sent the presentation slides and a gift to the Elder as a token of my appreciation for her participation in the CAG. During the meeting, I discussed the objectives of my study and my expectations from the CAG. Elder Jean imparted her wisdom and blessed the research project. The other members reminded me of the importance of conducting Indigenous research with the involvement of the CAG.

3.4.2.2.2 Community Engagement

As stated above, Maamwesying North Shore Community Health Services and Noojmowin Teg Health Centre supported and guided me in my research process. I started developing the Research Agreement document and discussed it with Noojmowin Teg and Maamwesying. In the meantime, I was looking for communities with which to establish partnerships for the research project. Within Manitoulin Island, there are seven different First Nations communities- Aundeck Omni Kaning, M'Chigeeng, Sheguiandah, Sheshegwaning, White Fish River, Zhiibaahaasing First Nation and Wikwemikong Unceded Territory. I presented to the Manitoulin Island Community Advisory Council, which supported adapting and validating CICA. I reached out to Wikwemikong Health Centre and presented the research objective and expectation of potential partnership with the community to the Health and Social Well-being Committee so they could make recommendations to the Chief and Councils of Wikwemikong First Nation. I also emailed M'Chigeeng First Nations, looking to form a partnership with them.

As a Ph.D. student, time and funding constraints prevented me from reaching out to every community and Band Council to get permission to form partnerships and conduct research. Both Noojmowin Teg and Maamwesying as well as my supervisor advised me that it would be unrealistic as a Ph.D. student to include different communities as Indigenous communities are diverse. Thus, Maamwesying came forward and extended the hand of partnership in conducting my research.

3.4.2.2.3 Maamwesying North Shore Community Health Services

Maamwesying is an Indigenous health service organization delivering quality primary and therapeutic health care to all individuals in its member communities and the urban Indigenous population residing in Sault Ste. Marie. Maawesying provides outreach and collaboration services to eleven First Nation communities and one Indian Friendship Centre through N'Mninoeyaa Health Access Centre. Maamwesying's partnered First Nations communities include Atikameksheng Anishnawbek, Sagamok Anishnawbek, Serpent River First Nation, Mississauga First Nation, Thessalon First Nation, Garden River First Nation, Batchewana First Nation, Michipicoten First Nation, Chapleau Cree First Nation, Chapleau Ojibwe First Nation, and Brunswick House First Nation. Baawaating Family Health Clinic primarily provides services to the off-reserve Sault Ste. Marie population, as well as non-Indigenous residents.

In Ojibway, an Indigenous language, Maamwesying means “the act of working as one.” Maamwesying's vision is to “work as one for the wellbeing of all.” Maamwesying works with its community partners to provide accessible, quality, culturally safe, and holistic care that supports and enhances the wellness of individuals, families and communities. In a collaborative partnership with Health Sciences North Research Institute (HSNRI) and Noojmowin Teg Aboriginal Health Access Centre, Maamwesying is involved in two research projects- Model for Indigenous Dementia (MiND) Care and Wholistic Integrated Safe and Effective (WISE). These research projects are helping to build sustainable community-owned and directed strategies that support healthy aging, the needs of older adults with multiple chronic conditions and dementia care in First Nations communities, with

a focus on cultural safety and trauma-informed care. Moreover, Maamwesying, in partnership with the Superior Family Health Team, provides dementia care services in First Nation communities using the Multi-Specialty Interprofessional Team Memory Clinic (MINT). Maamwesying is also using the CICA tool to assess dementia in the community.

3.4.2.2.4 Partnership with Maamwesying North Shore Community Health Services

I reached out to the Director of Home and Community Care at Maamwesying North Shore Community Health Services, Edith Mercieca, for partnership. She has been the community principal investigator leading the dementia related projects at Maamwesying and is highly regarded for both her research and her innovation in delivering health care services. Thus, she became the focal person at Maamwesying for me to discuss our project. In partnering with Maamwesying North Shore Community Health Services, Maamwesying and I were equally involved in setting the direction of the research, working equitably based on our abilities and time availability, and the outcomes were jointly and openly defined. In the research process, the outcomes may not have been the same for both of us- me and Maamwesying, but we were aware and respected what we wanted from this research and how the research outcome would be used, and we both reached consensus through discussion. We focused on equality and equity in the partnership by recognizing the structural, financial and power differentials through communications.

Researchers working with the communities need to be honest and transparent. Honesty of a researcher means being able to communicate the purpose and expected outcomes of the research both for the community and for oneself. I was clear with

Maamwesying about the requirements of my program. Maamwesying also communicated with me the need for them to develop a functional assessment tool to be used in their communities, along with the CICA to inform a culturally safer approach to the diagnosis of dementia.

3.4.2.3 Health Professional Focus Group

I conducted focus groups with health professionals involved in assessing Indigenous people's cognitive and functional decline to understand their experiences and perspectives. The aim was to explore the domains of a culturally relevant and appropriate functional assessment tool. As stated above, community members and clinicians expressed the need for an informant-based functional assessment tool that can be used along with already developed culturally appropriate and relevant cognitive assessment tools. Understanding the perspectives of those who use such assessment tools, namely health professionals, is crucial before developing a new tool.

Indigenous primary health care (PHC) services were established in response to the inadequacy of mainstream health services in meeting the needs of Indigenous communities. These PHCs are managed by and for the Indigenous population and are aligned with the community values and principles. Primary health care workers within Indigenous PHCs have played a significant role in delivering health care to Indigenous peoples. Studies have demonstrated that these health professionals have improved the uptake of preventive services, screening programs and chronic disease treatment by facilitating culturally appropriate care, reducing communication gaps and strengthening referral linkages (Jennings

et al., 2018; Jeyakumar et al., 2023; McDermott et al., 2015; Topp et al., 2021). Given their significant role in delivering the appropriate health care, they are aware of the needs of the communities. Thus, I aimed to understand the perspectives of Indigenous and non-Indigenous health professionals who provide dementia-related care and services to Indigenous communities. This focus group explored their experiences in assessing functional decline in patients presenting cognitive complaints and the challenges encountered in this process. Furthermore, the focus group aimed to explore the domain of IADLs within Indigenous cultural contexts and approaches to culturally safe assessments. Thus, it is crucial to understand the health professionals' perceptions as they are the ones who utilize the tool daily.

3.4.2. 4 Participants Sampling

Purposive sampling was used to select participants in the focus groups. Purposive sampling aims to create an in-depth understanding of the phenomenon under study, which was preferred to a sampling method for ensuring the generalizability of the findings (Palinkas et al., 2015). Both Indigenous and non-Indigenous health professionals who work closely with people living with dementia and provide cognitive and functional assessment and services were included in the sample.

This study targeted a sample size of 15-20 participants. This sample size is sufficient in qualitative research to produce meaningful analyses from focus groups (Vasileiou et al., 2018). Focus groups involve the interaction of group participants with each other as well as with the moderator. A focus group is generally conducted to collect research data based on

the perception and experiences of the participants (Carlsen & Glenton, 2011). It is the collection of this kind of interactive data which distinguishes the focus group from the one-to-one interview, as well as from procedures which use multiple participants but do not permit interactive discussion. Typically, focus groups consist of 6-8 participants, rarely exceeding 12, and often consists of pre-existing groups of people, usually homogenous groups (Busetto et al., 2020).

3.4.2.5 Participants Recruitment

In Indigenous research practices, participants are often contacted through family relations or friends (Wilson, 2001). Such relations have practical uses in establishing rapport with research participants, and the researchers will also be within a circle of relations. This helps enforce the accountability of the researchers, as they are responsible not only to themselves but also to the circle of relations and make it much easier for the researcher and participants to converse and ask questions regarding the research, objectives and motivation behind the research projects.

Likewise, the recruitment of the participants was based on a highly relational approach, built upon previously established relationships of my supervisor with potential participants and organizations, the academic and Indigenous advisory committee members, and other colleagues. With the support and guidance of Maamwesying, I presented my research project to the Health Directors of eleven First Nations Health Centres, Maamwesying Ontario Health Team Steering Committee, Primary Health Care Team in Sudbury, Home and Community Support Services several times in-person and online to help

recruit the potential participants for the focus groups. Online and on-site study presentations ranged from formal to more informal talks, offering opportunities for organizational staff and leaderships to get to know about research, its purpose, potential community benefit, focus group participation details and confidentiality measures. I also handed out research information (Appendix C), which contained a short summary and relevant information about the research, including my and my Edith's contact information.

During the presentation, when an individual expressed potential interest, I sent a follow-up email providing details of the research with an invitation to participate into a focus group. Edith personally emailed potential participants with a recruitment poster and a brief overview of the research project, followed by a subsequent follow-up. The recruitment poster is provided in the (Appendix D). Additionally, a recruitment poster was published in an internal newsletter of Maamwesying, inviting interested individuals to participate in the focus groups to email me. Furthermore, a health professional from Atikmeksheng Anishnawbek health services helped in contacting possible participants with the recruitment poster and asked them to participate by word of mouth.

Additionally, the Superior Family Health Team (SFHT) expressed their interest in participating in the focus group. The Executive Director (ED) of SFHT had attended my presentation in one of the meetings and expressed willingness to assist Maamwesying in developing the Indigenous Functional Assessment tool. This team is a primary health care provider in Sault Ste. Marie offering integrated dementia assessment and care services. I contacted the ED via email and provided a recruitment poster and a brief detail about the project for distribution among eligible staff members. She asked me to present my research

objective and expectations to her staff, and she played a crucial role in recruiting the potential participants.

3.4.2.6 Data Collection Methods and Procedures

The primary tool of this qualitative study was focus groups with health professionals which I described in an earlier section 3.4.2.3.

3.4.2.6.1 Focus Group Discussion

I conducted two focus groups with the health professionals. The first focus group was hybrid in style including in-person and online participation and lasted 120 minutes. The second focus group was conducted in-person with 120 minutes. Before the start of the focus group, I obtained consent from participants. As part of the consent process, I introduced the projects and provided the verbal summary of the study, including its objectives and methods, as outlined in the research summary included on the consent form. I ensured that participants understood that the participation was voluntary, and they had the right to: (a) refuse or withdraw from the study at any time; (b) ask any questions about the research during or following a focus group; and (c) stop the interview at any time. To further promote informed and voluntary consent, I carefully explained the measures taken to protect participants' confidentiality, stressing that except for me and my supervisor, no one would have access to any of the information provided. Finally, I emphasized that the purpose of this study was not to evaluate but rather to analyze the data using the principles of Ownership, Control, Access and Possession (OCAP®).

The participants were asked to complete the consent form (Appendix F). With the permission of participants, I audio and video-recorded the focus groups, and took field notes after the focus groups as I reflected on the session. The writing of field notes helped me to organize my evolving thoughts as I moved back and forth between data collection and analysis.

During both focus groups, one of my classmates helped me in facilitating the sessions. She signed the confidentiality agreement (Appendix G) before data collection and accompanied me to the data collection site. Her responsibilities included managing the technical aspects such as operating audio and video recording equipment and distributing and collecting informed consents.

A focus group guide (Appendix E) was developed in alignment with the overall purpose and objectives of the research and in consultation with my doctoral supervisors. The focus group guide included a set of prompt questions such as Indigenous views on dementia, experiences of using existing functional assessment tools with challenges faced by health professionals and potential functional assessment tool designed to elicit participants' experience and perspectives on the approaches and domains to be used while developing a culturally appropriate functional assessment tool. Based on participants' experiential accounts during the focus groups process, I formed subsequent follow-up questions.

While these prompt questions were open-ended and exploratory in nature, they were also semi-structured. The whole discussion was around their experiences on the design, approach and necessary domain of the tool. At the end of the session, I asked participants if there was anything important they felt was missing. While focus group guides for both

sessions were similar, I adjusted the guide for the second focus group to better capture the differential experiences associated with participants' different positioning across the use of tools.

Acknowledging that sharing food is an important cultural aspect and a symbol of trust in Indigenous communities, I discussed food preferences for participants with the Home Care Manager. She took on responsibility of managing food for the participants. After completing the session, I gifted all the participants with a gift from Nepal. An honorarium of \$50 was provided by Maamwesying to all participants. For the second focus group, the ED of the SFHT managed coffee and snacks for the participants as a way to support the work.

3.4.2.7 Data Analysis and Iterative Community Input

I undertook an iterative and nonlinear approach to thematic analysis using methods described in the literature for analyzing qualitative data (Braun & Clarke, 2006; Thorne, 2016). Braun and Clarke proposed a six-phase process (i.e. familiarizing with your data, generating initial codes, generating themes, reviewing potential themes, defining and naming themes and producing the report) to facilitate analysis and help researchers focus on thematic analysis. Although the six phases are organized logically and sequentially, the data analysis was not linear but recursive and iterative, requiring the researcher to move back and forth through the phases as needed (Braun & Clarke, 2021). The data analysis was more inductive in nature. The inductive process emphasized that meanings were derived from the respondents or data (Byrne, 2022). The following steps highlighted the different stages of

data analysis; however, the process unfolded more in a cyclical manner than in a linear fashion.

Besides, following the six-phase process by Braun and Clarke, that will be outlined in the sections below, additional steps were included in the thematic analysis that pertained to the community-based approach with Indigenous communities. The additional steps that were included pertained to phase four where potential themes were reviewed. Maamwesying, organized a research symposium in April 2023, to learn about community-based research and First Nations community research ethics, networking with community members, community partners and research team, discuss research links to community priorities and explore a Maamwesying research unit. Being a research partner, Maamwesying offered the opportunity for me to present preliminary results to the participants at the symposium. It was an opportunity for me to showcase my preliminary results to representatives from my CAG, Senior PAC, my supervisor, and other Indigenous and non-Indigenous researchers and community members. Three of my focus group participants were present at the symposium and they appreciated that their voices were captured in the study results. Similarly, in May 2023, I presented the preliminary results to a meeting of Indigenous and non-Indigenous researchers and clinicians working together on issues in dementia care for Indigenous populations. The reflections on the feedbacks and comments from both of the events helped me in finalizing the themes and developing an overall story about the data. It is important to acknowledge these additional steps were undertaken as a change to mainstream methods while working in collaboration with Indigenous communities. By incorporating additional revisions based on input from the broader community, we ensure that the knowledge

gathered is shared in a respectful and culturally appropriate manner, aligning with community acceptance and approval.

Phase 1: Familiarizing with your Data

After completing both focus groups, I listened to the audio recordings to familiarize myself with the data. This involved actively listening to each focus group without taking notes, which helped me understand the primary areas addressed by the focus group. The second focus group was conducted 20 days after the first session and was influenced, to some extent, by my initial thoughts, interpretations and questions from the first session (Nowell et al., 2017). During both focus groups, I documented my thoughts during and after data collection, and this marked the beginning of data analysis. Active listening to both sessions after data collection helped me recall gestures and mannerisms and the context of the discussion. Afterwards, I transcribed both recordings verbatim into Windows Microsoft Office Word documents.

After transcription, I checked the transcripts for accuracy against the original audio recordings. As part of this process, I removed identifiable information, such as names of people, replacing them with categorical codes. Then, I uploaded both transcripts into an electronic database using NVivo® (Lumivero, 2023), a qualitative software program for data management, organizing and coding.

After uploading the transcripts, I read each transcript several times, familiarizing myself with the data. It is crucial for researchers to immerse themselves to understand the depth and breadth of the content (Braun & Clarke, 2006). While reading the transcripts, I

highlighted potentially interesting passages. I documented the theoretical and reflective thoughts I developed through immersion in the data, including my values, interests, and growing insights about the research topic (Nowell et al., 2017).

Phase 2: Generating Initial Codes

After familiarizing myself with the data, documenting my thoughts and reflection, and uploading it on NVivo, I revisited the data and searched for the initial codes. It involved working systematically through the entire dataset, giving equal consideration to all data. I selected important text sections and labeled them by focusing on generating codes that helped address the research question (Byrne, 2022). As Braun & Clarke (2006) mentioned, I, too, coded sections of the text in as many different themes as they fit, being uncoded, coded, or coded as many times as I found relevant. Through repeated iterations of coding and further familiarization, I could identify the codes that could be discarded.

I coded the entire data set in NVivo ® (Lumivero, 2023) with several codes. In this phase, I consulted with my supervisor and a supervisory committee member with qualitative research expertise to debrief how my thoughts and ideas evolved as I engaged more deeply with the data. I shared my data analysis plan and use of thematic analysis. They provided me with some of the references on thematic analysis and described the crucial steps to consider while conducting thematic analysis.

Phase 3: Generating Themes

I covered a wide variety of concepts in the focus groups as this was the first known research to understand health professionals' perspectives regarding the functional assessment tool in the Indigenous context. Rather than interpreting individual data, my focus shifted towards interpreting aggregated meaning and meaningfulness across data (Byrne, 2022). I reviewed, analyzed and combined multiple codes according to the shared meaning into themes and sub-themes. My main motive behind this process was to ensure that the pattern of codes was able to illustrate something meaningful that helped answer the research questions (Clarke & Braun, 2013).

During the process, a miscellaneous theme was generated to contain all the codes that do not fit in among any prospective themes. Some codes within the miscellaneous themes fit in different themes and others were removed from the analysis.

Phase 4: Reviewing Potential Themes

During this phase, I reviewed the coded data extracts for subthemes to see if a coherent pattern could be observed. While going through the themes, I presented the preliminary results at a research symposium and in a meeting with Indigenous and non-Indigenous researchers and scholars which I described above. Presenting preliminary results with the broader community, helped me in revisiting the themes and subthemes and deciding that some themes did not have enough data to support them, some needed to be merged, and some new ones were formed. The comments and feedback on the themes and sub-themes

helped me to fit them together and develop an overall story about the data. The feedback and comments from my supervisory committee members further enhanced this analysis.

Phase 5: Defining and Naming Themes

During this phase, I conducted a detailed analysis of each theme. I identified narratives conveyed by each theme while considering how each theme fit into the overall narrative of the entire data set about the research questions. Although I was involved in data analysis alone, I consulted with my supervisory committee, who were experts on qualitative methods and Indigenous health research. Also, presenting to the research symposium and Indigenous research meeting helped to ensure that the themes were sufficiently clear and comprehensive to conclude modifications (Byrne, 2022). Lastly, I sent the draft of my results to the supervisory committee for review.

Phase 6: Producing the Report

As the write-up of qualitative research is deeply intertwined with the entire process of the analysis (Clarke & Braun, 2013), the codes and themes continued to evolve throughout the analysis along with the write-up. I had several drafts of my writing during the process, which helped me produce the final analysis of my data. During this phase, my focus was on establishing the order of the themes logically and meaningfully, building a strong narrative of the data (Byrne, 2022).

3.5 Ethical Considerations

Ethical considerations are of fundamental importance to the researcher and were addressed in several different ways. Firstly, I sought ethical approval (Appendix A) for this project through the Laurentian University Research Ethics Board (LUREB), which approved the research after an in-depth ethical review of the proposed study, its procedure, methods and forms.

These procedures included strategies for assuring both participants and institutional/organizational confidentiality. I discussed methods for ensuring confidentiality with prospective participants and representatives of potential community partners as part of the consent process (described previously in more depth) prior to the commencement of any individual data collection. I removed all possible identifying information from the transcripts and computer files and replaced it with alphanumeric codes. The Excel spreadsheet that linked the code assignment to participants and institutions/organizations with identifying information was password-protected, kept separately from the data set, and was only accessible to my supervisor and me. In addition, I paid special attention to ensure that participants were informed that their involvement in this study was voluntary and would not affect their employment or related performance evaluations. Ethics approval with LUREB was maintained throughout the entire research process.

Secondly, in keeping with the Indigenous Research Paradigm and CBPR approach, I sought to undertake research that was informed by and consistent with ethical recommendations and guidelines for Indigenous health research. In particular, the research was guided by the ethical principles of Ownership, Control, Access and Possession

(OCAP®) (First Nations Information Governance Centre, 2020), the Canadian Institute of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People (CIHR, 2007), and Chapter 9 of the Tri-Council Policy Statement, which outlines strategies for ensuring that research findings benefit Indigenous peoples and communities.

Following the OCAP® principles, Maamwesying exercises ownership, control, access and possession over the research process and the final results. I audio-recorded the focus group using a recorder provided by my department while video-recorded on my personal laptop. The audio was transferred to my password-protected laptop and subsequently deleted from the recorder to ensure data security. Both audio and video recordings were then uploaded to the password-protected Laurentian University Google Drive. Currently, I have the focus group data and the results on my computer. I had a meeting with Maamwesying to discuss the data sharing plan. As Maamwesying is developing its data governance plan, I will hand over all data and results to them. If I need access to the data in future, I will seek permission from Maawesying.

Due to resource constraints in providing data analysis software NVivo ® by Maamwesying, I obtained a student version with my supervisor's support. The transcribed focus group discussions were uploaded to my NVivo ® account, which is password-protected. Although I have data stored on my password-protected personal computer, it will be shared with Maamwesying before the completion of my research.

As per the requirement for my doctoral degree, I must submit a thesis to the Laurentian University, granting the university copyright over the thesis. However, all final results and findings generated from the research belong to the Maamwesying. Also,

Maamwesying will co-author the articles for publication. Prior to engaging in any future publications, Maamwesying and CAG will be consulted for confirmation and approval will be sought from. Additionally, I will get confirmation and approval from Maamwesying before using the collected data for further research.

Chapter 4

4. Results

In this chapter, I predominantly focus on the results of my research objectives. In the previous chapter, I described the methods and the framework I used for my study. Here, in the first part, I describe the results of my scoping review, where I used the Indigenous Wholistic framework to analyze the selected articles. In the second part, I present the results from the focus groups conducted with the Indigenous and non-Indigenous health professionals to understand their perspectives on the functional assessment tool for dementia to be used in an Indigenous context. The results of the scoping review guided the overall conduct of the second part of the study.

4.1 Phase I- Scoping Review Results

4.1.1 Selection of Sources of Evidence

A total of 2426 articles were identified from six databases- PubMed, APA Psych Info, CINAHL, Medline, Web of Science, Bibliography of Native North Americans, Australian Indigenous Health info data set, and Indigenous Health Portal of the University of Saskatchewan. After removing duplicates, 1751 articles were found, and following a reassessment of the initial decisions made during the first review phase, 88 manuscripts were selected for full-text review. Twelve additional articles were identified by reviewing

reference lists of the full-text articles. The full-text review removed 44 articles. From the full-text review, 36 relevant papers were selected, representing 30 individual instruments. All the manuscripts were written in English. Please see Figure 2 for the PRISMA diagram for an overview of the screening process results.

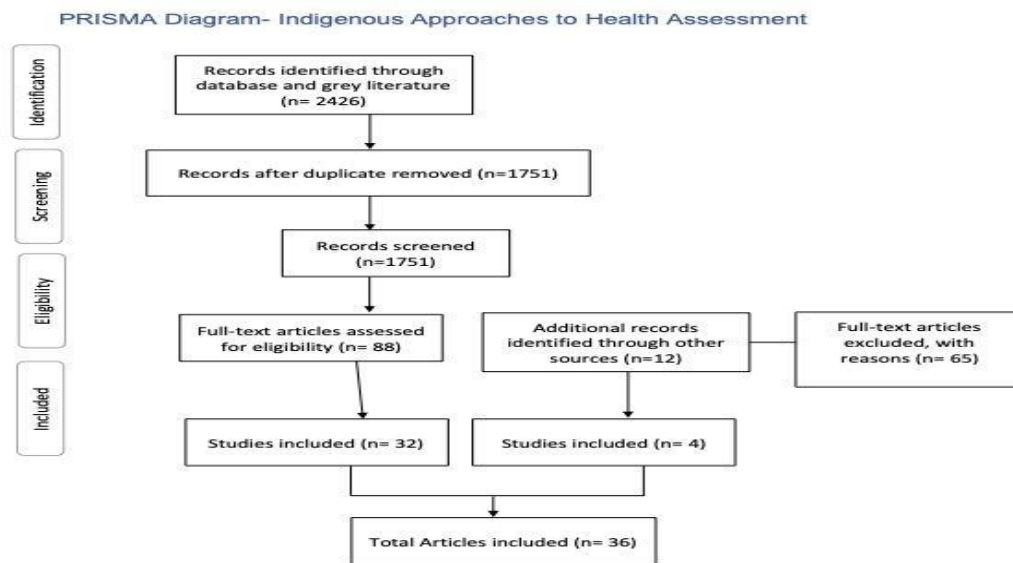


Figure 2 PRISMA-ScR flowchart showing selection of articles for scoping review

I present the results in two ways: 1) characteristics of the included studies (i.e., numerical overview of the amount, type/methods and distribution of the included literature), and 2) using the Indigenous Wholistic Framework to synthesize and map the results.

4.1.2 Analysis of the Characteristics of the Included Studies

In the 36 studies, there were 30 unique tools described that were translated, adapted or developed using Indigenous approaches or methods. Most of the studies were conducted in Australia (n=24), followed by Canada (n=6), USA (n=3), and Aotearoa/New Zealand (n=3) (Figure 3). The selected articles discussed the methodology and methods involved in either modifying existing or creating new tests/questionnaires for Indigenous populations across Australia, Aotearoa/New Zealand, Canada, and the United States.

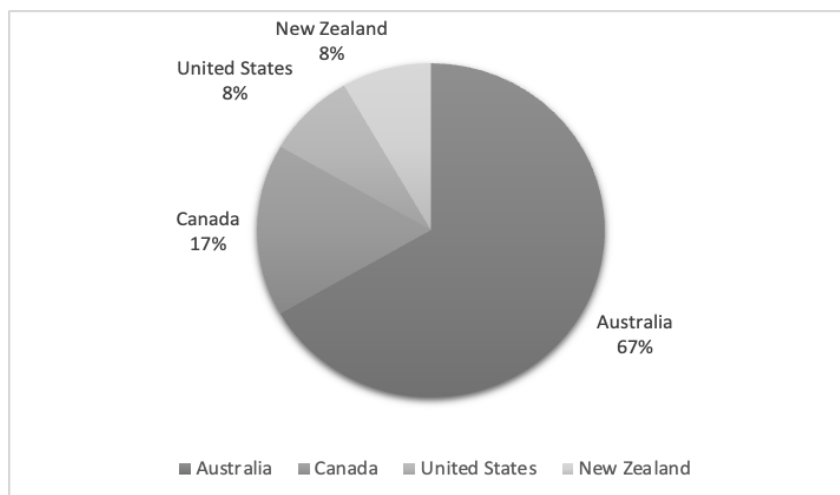


Figure 3 Percentage of selected articles by country

Of the 36 articles published between 2001 and 2021, more than 80% were published after 2010 (Figure 4). Six articles were published in 2021, preceded by five in 2016. Before 2010, only seven articles were published.

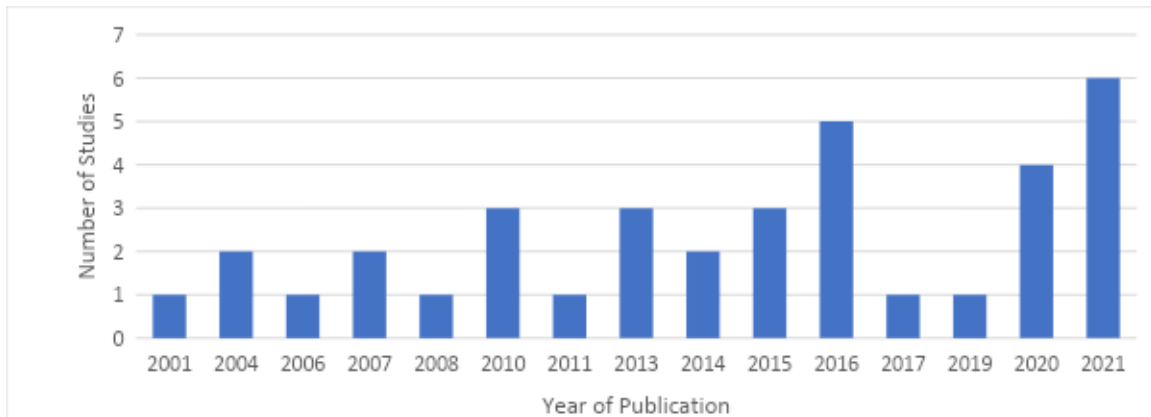


Figure 4 Number of studies as per the year of publication

Among 30 tools, seven were adapted to Indigenous contexts, one was translated, and the remaining 22 were developed specifically for Indigenous people. Among those seven tools, two Indigenous-specific health assessment tools were adapted in different Indigenous contexts. Based on the population group, seven tools were focused on children, two on youths and 21 on adults (Table 3).

Table 3 Number of tools as per population

Target Group	Number of Tools (n=30)
Children	7
Youth	2
Adult	21

Areas covered included psychological stress and depression among men and women, cognition, communication disorders in adults and children, speech and language problems in

children, hearing and listening difficulties in children, early communication development, developmental disability among children, social and emotional well-being among youth and adults, a medical and developmental checklist to investigate the incidence of conditions such as Fetal Alcohol Syndrome Disorder (FASD), alcohol and drug issues and mental health issues, musculoskeletal conditions, sleep apnea in older adults, occupational stress and well-being, and health-related quality of life (Table 4). The tools reported the ethnic identities of study participants as “Aboriginal and Torres Strait Islanders,” “Indigenous Australians,” “Aboriginal,” “Native Hawaiians,” “American Indians,” “Māori” and “First Nations.”

Table 4 Aspects of health measured by the tool

Measure	No. of tools (n=30)
Health and well-being	10
Mental health, alcohol and drug use	5
Child's development (developmental disability, communication development and disability)	5
Quality of life	3
Cognition	3
Aphasia	1
Sleep Apnea	1
Musculoskeletal	1
Fetal Alcohol Spectrum Disorders	1

4.1.2.1 Methods for Adaptation and Development of Tool

Methods were defined as standardized processes or steps that facilitate the process of adaptation or development of the health assessment tool. The majority (n= 25) of the tools used more than one method for adapting or developing the health assessment tool. Methods included: focus group (n=10), interviews (n=8), literature review (n=10), discussion with experts (n=3), and consultation with diverse Indigenous and non-Indigenous councils, communities and Elders to various extents (n=23). Additional Indigenous methods applied in the studies were yarning (n=4) and photovoice (n=1). Details of the methodology used in various studies for adapting and developing the tool have been provided in the table in Appendix H (Table 5).

4.1.3 Analysis Using the Indigenous Wholistic Framework

In this section I described the Indigenous Wholistic Framework (Pidgeon, 2016), as was described in Chapter 3, to interpret the results of the scoping review. In this section, I describe the use of the framework in relation to my study. The concepts related to the 4Rs (respect, relevance, responsibility and reciprocity) are difficult to interpret in isolation as they are interrelated and complement each other; however, I tried to offer my conceptualization of the 4Rs in relation to the articles selected in the scoping review.

Respect

The majority of the tools in my review have, in one way or the other, considered and acknowledged the local knowledge and expertise grounded in the culture and language of Indigenous communities (Almeida et al., 2014; Amberber, 2011; Barraza & Bartgis, 2016; Benn et al., 2021; A. D. Brown et al., 2013; Butten et al., 2021; Campbell et al., 2008; D'Aprano et al., 2016; J. P. Fitzpatrick et al., 2013; Gomez Cardona et al., 2021; Haswell et al., 2010; Jacklin et al., 2020b; Janca et al., 2015; Kotz et al., 2016; LoGiudice et al., 2006b; Marley et al., 2017; Peters & Peterson, 2019b; K. Smith et al., 2007, 2021; Thomas et al., 2010; Young et al., 2013, 2015). More researchers are beginning to use Indigenous knowledge as a framework to guide their research while conducting Indigenous health research; however, relatively few describe how this knowledge was included in their study (Pidgeon & Riley, 2021). Some of the Indigenous frameworks used to guide the adaptation and the development of the tool were the Medicine Wheel (Barraza & Bartgis, 2016; Young et al., 2013, 2015), the Wholistic approach to health (Butten et al., 2021; Peters & Peterson, 2019b; Thomas et al., 2010), the Māori model of health (Palmer, 2004; Stewart & Gardner, 2015), and the Indigenous research paradigm (Jacklin et al., 2020b; Peters & Peterson, 2019b). Furthermore, various approaches were used in adapting and developing the tool rather than a single one. Some of these were the trauma-informed approach (Jacklin et al., 2020b), yarning approach (Janca et al., 2015; Kotz et al., 2016; Marley et al., 2017; K. Smith et al., 2021), strength-based approach (Barraza & Bartgis, 2016; Peters & Peterson, 2019b), two-eyed seeing approach (Jacklin et al., 2020b), decolonizing approach (Gomez Cardona et al., 2021), valuing Indigenous self-knowledge over expert perspectives (Haswell et al., 2010;

Peters & Peterson, 2019b), the interconnectedness of health as the Indigenous construction of well-being (A. Brown et al., 2016; Kotz et al., 2016; Marley et al., 2017; Peters & Peterson, 2019b; K. Smith et al., 2021), and concept of spirit as central to the physical, emotional and spiritual well-being of Indigenous people (A. Brown et al., 2016; K. Smith et al., 2021). Most of the instruments were developed in the context and realities of Indigenous peoples' lives and languages and expressed specific health conditions. Some tools replaced the Western concept with an Indigenous concept while defining the condition or items and domains. While developing the *Kimberley Indigenous Cognitive Assessment (KICA)* tool, researchers used the Indigenous concepts of number, time and space, which differs from Western concepts (LoGiudice et al., 2006b). Similarly, Brown (2019) conducted a qualitative study to conceptualize depression in men from an Indigenous concept rather than using a pre-existing Western concept of depression (A. D. Brown et al., 2013).

Community advisory groups (Barraza & Bartgis, 2016; Jacklin et al., 2020b; Kotz et al., 2016; Marley et al., 2017; Young et al., 2013, 2015), Indigenous reference groups (Campbell et al., 2008; Hayes et al., 2010; Janca et al., 2015) or Elder governance groups (K. Smith et al., 2021) were formed to ground the health assessment tools in local knowledge and context. These groups or councils were meant to guide the research process. Some of the tools detailed how the reference group or advisory group was responsible for different research steps, and some did not. While developing the *KICA* tool, the research team responsibly engaged with local Indigenous people and followed their cultural rules as a way of respecting traditional Indigenous knowledge (LoGiudice et al., 2006b). Furthermore, some tools were adapted or developed using plain English language as most Indigenous

communities across the countries use a different dialect of the English language rather than “standard English” (A. D. Brown et al., 2013; Campbell et al., 2008; D’Aprano et al., 2016; J. P. Fitzpatrick et al., 2013; Hayes et al., 2010). Some tools were translated into Indigenous languages (J. P. Fitzpatrick et al., 2013; Jacklin et al., 2020b; Janca et al., 2015; LoGiudice et al., 2006b). Bilingual translators, sometimes referred to as the ‘Language Center Group,’ were used to ensure the tools were translated into local languages (Amberber, 2011; Jacklin et al., 2020b; LoGiudice et al., 2006b).

Elders were part of the research process; they provided wisdom and guidance on all aspects of the study and were essential in ensuring the cultural relevance of the work (Jacklin et al., 2020b; Young et al., 2013, 2015). As ceremony is an essential part of Indigenous research, Young et al. (2013, 2015) initiated the data collection with a prayer and smudging ceremony led by a local Elder, consistent with local cultural tradition. Some tools were developed following the community’s protocols (Gomez Cardona et al., 2021; Jacklin et al., 2020b; Young et al., 2013, 2015). In addition to a university’s research ethics board, some communities have developed their own research ethics board and community protocols to be followed. The *Kanien’kéha- Growth Empowerment Measure (K-GEM)* and *Canadian Indigenous Cognitive Assessment (CICA)* tool recognized community protocols and respected the ethical framework in Indigenous contexts consisting of respect, equity, and reciprocity principles (Gomez Cardona et al., 2021; Jacklin et al., 2020b).

Relevance

Relevance refers to the meaningfulness of the research project for the chosen Indigenous communities. Researchers were aware of the socio-ecological context of the communities (A. D. Brown et al., 2013; Butten et al., 2020, 2021; Campbell et al., 2008; Dionne et al., 2014; Hayes et al., 2010; Kotz et al., 2016; Schlesinger et al., 2007; K. Smith et al., 2021) and understood the impact of historical and contemporary realities of Indigenous communities (J. P. Fitzpatrick et al., 2013; Jacklin et al., 2020b; LoGiudice et al., 2006b; Schlesinger et al., 2007; Thomas et al., 2010). Instead of using the Western label of symptoms of depression, Brown et al., (2013) conducted qualitative research to conceptualize depression for men in an Indigenous context. Indigenous communities are culturally diverse, and the "one-size fits all" approach is not applicable in terms of a health assessment tool's applicability and acceptability across communities. This was further supported while adapting the *Growth and Empowerment Measure (GEM)* tool, originally developed to measure well-being in Australian Indigenous populations, for use in the Canadian Mohawk community. While adapting the tool, an emic approach was applied wherein a tree metaphor from the original Australian tool was adapted into a "cycle of season" metaphor within the Canadian context and various trees were used to represent different seasons (Gomez Cardona et al., 2021). This emic approach, which sensitizes to a specific community's culture and history, is necessary while adapting or developing a tool.

All of the health assessment tools that were either adapted or developed in the Indigenous context should be meaningful or useful to the community. However, the review suggested that the research needs mainly were identified by the researchers rather than the

community themselves (Almeida et al., 2014; Amberber, 2011; Benn et al., 2021; A. Brown et al., 2016; A. D. Brown et al., 2013; Butten et al., 2020; Campbell et al., 2008; Ching, Hou, et al., 2020; Ching, Saetre-Turner, et al., 2020; D'Aprano et al., 2016; J. P. Fitzpatrick et al., 2013; Gupchup et al., 2001; Haswell et al., 2010; Janca et al., 2015; Kotz et al., 2016; LoGiudice et al., 2006b; Marley et al., 2017; Palmer, 2004; Peters & Peterson, 2019b; Schlesinger et al., 2007; K. Smith et al., 2016; Stewart & Gardner, 2015; Thomas et al., 2010; Vindigni et al., 2004; Young et al., 2013). Very little research was developed in response to the needs identified by, and in partnership with, Indigenous communities (D'Aprano et al., 2016; Jacklin et al., 2020b). At the same time, some researchers conducted preliminary qualitative studies involving Indigenous peoples to identify the needs of the communities (Kotz et al., 2016). Some researchers worked closely in community collaboration, presenting the objectives, methods, and expected outcomes to senior Indigenous community leaders to explain the project, its ethical considerations, and expected benefits to the communities before starting the research (A. Brown et al., 2016; Janca et al., 2015). This highlighted the importance of placing Indigenous ideologies of Indigenous peoples at the center of an initiative rather than receiving the end of Western ideology and health care.

Very few tools developed were consistent with the Indigenous worldviews and holistic character of complete well-being (Palmer, 2004; Peters & Peterson, 2019b). The contents of the tools were closely connected or appropriate to the lived experiences, perspectives, priorities, and ways of knowing, living, and doing in Indigenous communities and were developed in collaboration and consultations with the communities (Jacklin et al.,

2020b). The researchers were aware of the impact of colonization on Indigenous communities and the historical failure to privilege Indigenous ways of knowing. Many used culturally appropriate pictures, figures, and illustrations using local artists to promote decolonization (Amberber, 2011; Ching, Hou, et al., 2020; D'Aprano et al., 2016). Importantly, Elders often contributed throughout the research process. Some research has involved Indigenous communities with a wide range of language groups and developed tools using words and sentences in plain English as a local dialect, reflecting the community's socio-cultural context. Some tools were designed keeping in mind the sensitivity of the issue, and used a community navigator for their administration (J. P. Fitzpatrick et al., 2013).

Responsibility

Indigenous people focus on the importance of relationality and the interconnectedness of their lives with their communities (Wilson, 2008). In Indigenous research, relationships between the researcher, research team and the Indigenous community are of paramount importance. Consequently, the researcher bears responsibility not only to the participants, but also to the communities, research topics, and design, with accountability for the impact of research on individuals and communities (Snow et al., 2016). Thus, the researcher must engage in discussion and dialogue with the communities about the objectives and motivation of the research, inform the communities about the potential risks, benefits, and harms of the study, and jointly seek better ways of conducting research.

All tools were, to some extent, adapted or developed with the involvement of Indigenous community members or Indigenous health workers. Several tools reported

engagement with communities during the data collection stage and refinement of the tool based on the feedback of the community members and Indigenous health professionals (Almeida et al., 2014; Amberber, 2011; Benn et al., 2021; Ching, Hou, et al., 2020; Ching, Saetre-Turner, et al., 2020; Dionne et al., 2014; J. P. Fitzpatrick et al., 2013; Palmer, 2004; Schlesinger et al., 2007; Vindigni et al., 2004). Except for Gupchup (2001), who conducted a four-hour focus group with older patients with asthma to adapt the *Asthma Specific Quality of Life Questionnaire* (Gupchup et al., 2001), all other tool adaptation and development processes consisted of some form of consultation with the community members and Indigenous health professionals at different stages of the research process. In some cases, engagement with the Indigenous community members occurred from the very beginning (Barraza & Bartgis, 2016; A. Brown et al., 2016; Butten et al., 2021; Campbell et al., 2008; D'Aprano et al., 2016; Gomez Cardona et al., 2021; Haswell et al., 2010; Jacklin et al., 2020b; Janca et al., 2015; Kotz et al., 2016; LoGiudice et al., 2006b; Peters & Peterson, 2019b; K. Smith et al., 2016, 2021; Stewart & Gardner, 2015; Thomas et al., 2010; Young et al., 2013).

Tools such as *Here and Now Aboriginal Assessment*, *KICA* and *Men, Hearts and Minds* (A. Brown et al., 2016; Janca et al., 2015; LoGiudice et al., 2006b) were developed in collaboration with Indigenous communities through forming an advisory council or reference group. Their research teams consulted with advisory councils and reference groups to ensure the appropriateness and acceptability of the tool's methods, approaches and Indigenous cultural representation.

Over recent years, community-based participatory research methods have been used to conduct meaningful and relevant research with Indigenous communities (Castleden et al., 2012). Some tools have been adapted or developed using community-based participatory research (Barraza & Bartgis, 2016; Campbell et al., 2008; Gomez Cardona et al., 2021; Haswell et al., 2010; Hayes et al., 2010; Jacklin et al., 2020b; Kotz et al., 2016; Peters & Peterson, 2019b; K. Smith et al., 2021; Young et al., 2013, 2015) as well as incorporating an Indigenous community advisory committee. CBPR (Gomez Cardona et al., 2021; Jacklin et al., 2020b; Young et al., 2013, 2015) was alternatively used as participatory action research (Campbell et al., 2008) or community-based research (Haswell et al., 2010; LoGiudice et al., 2006b). CBPR ideally balances the power dynamics between the researcher and the participants, mainly the Indigenous people, prioritizing Indigenous sovereignty and self-determination, which aims to privilege the Indigenous voices in the research. In this case, researchers provided this committee with an outline of the research design, and the committee's request for modifications was considered and accepted through respectful cross-cultural dialogue.

While some studies did not partner directly with Indigenous communities and established an advisory council or reference group, several studies explicitly discussed their consultation process with key members of Indigenous communities. Consultation with Indigenous health workers and community members occurred at different stages (Amberber, 2011; Benn et al., 2021; Butten et al., 2020, 2021; Ching, Hou, et al., 2020; Ching, Saetre-Turner, et al., 2020; D'Aprano et al., 2016; J. P. Fitzpatrick et al., 2013; Jones et al., 2020; Stewart & Gardner, 2015; Thomas et al., 2010). Collaboration with the Indigenous

community health workers and Indigenous community members ensured that community guidance was available for all aspects of the research process by way of numerous community meetings.

Following the OCAP® principles is one of researchers' responsibilities to conduct research in "a good way" (Gomez Cardona et al., 2021; Jacklin et al., 2020b; Young et al., 2013, 2015). All tools developed and adapted in the context of Canada followed OCAP® principles.

Reciprocity

Reciprocity highlights research as part of gift exchange, including the gift of skills, knowledge, and experience (Barraza & Bartgis, 2016). Reciprocity has been discussed in the tool adaptation and development process in various ways.

Reciprocity means not only disseminating the study results with the intention that the research contributes to the local people's future well-being; the communities are also eager to receive tangible benefits while the researcher is among them (Paksi & Kivinen, 2021). Most of the tools were adapted or developed with the involvement of Indigenous Peoples and communities in different capacities; some tools were pilot-tested (Vindigni et al., 2004) and tested for reliability (J. P. Fitzpatrick et al., 2013; Peters & Peterson, 2019b) and validity in the same communities (Almeida et al., 2014; Benn et al., 2021; A. Brown et al., 2016; Butten et al., 2021; Campbell et al., 2008; Ching, Hou, et al., 2020; Ching, Saetre-Turner, et al., 2020; D'Aprano et al., 2016; Jacklin et al., 2020b; Janca et al., 2015; Jones et al., 2020; LoGiudice et al., 2006b; Marley et al., 2017; Schlesinger et al., 2007; Young et al., 2013,

2015). One of the best possible ways of giving back to the community is by adapting and developing the tool in the local community context that is relevant, appropriate, and embedded within traditional and local community knowledge, values, and beliefs. Peterson and Peters & Peterson (2019) suggested that the process of development of the *Wicozani instrument* was an opportunity for the communities to create their definition and factors of health as well as value their perspective and knowledge; it gave the individual power to create their narrative, identify who they are on their continuum of health, and take ownership of their own health. The Youth Council, which was formed to adapt the *Youth Personal Balance tool*, offered the tool as a gift to other communities (Barraza & Bartgis, 2016).

Similarly, while developing the *Here and Now Aboriginal Assessment* (Janca et al., 2015), the community developed its mental health glossary that defined mental health from their perspectives and worldviews. During the process, knowledge and skills were exchanged with Indigenous health workers and researchers. Among several other ways, one way to give back to the community was providing an honorarium to the Elders and participants to acknowledge and appreciate the time and knowledge they have provided to the research (Jacklin et al., 2020b; Peters & Peterson, 2019b). The research helped in building capacity within Indigenous communities by involving community members as research assistants. In some of the studies, community members and partner organizations were provided with the co-authorship in the publication (J. P. Fitzpatrick et al., 2013; Gomez Cardona et al., 2021; Jacklin et al., 2020b; Peters & Peterson, 2019b).

4.1.4 Summary

The scoping review, based on 30 tools, identified various methods and approaches used to adapt and develop health assessment tools within Indigenous contexts across Australia, Aotearoa/New Zealand, Canada and the United States. Over the last two decades, the use of Indigenous methods and approaches in the adaptation and development of assessment tools has notably increased. Furthermore, this review provided evidence that the tool adaptation and development process has shifted from previous expert-driven approaches to focus on engagement and consultation involving community members and Elders throughout every stage of the research process.

The concepts of respect, relevance, responsibility and reciprocity have been the foundation of most of the studies included in the review. While adapting and developing health assessment tools, researchers prioritized Indigenous concepts over Western concepts to ensure cultural appropriateness. Community protocols were followed throughout the process, and Community Advisory Groups, including Elders, played a crucial role in guiding research. Some Indigenous communities have established their own research ethics boards, ensuring community approval before initiating research projects.

Most of the tools were adapted and developed within Indigenous contexts, ensuring they were meaningful and beneficial to the community. Such tools were adapted and developed in collaboration and consultations with community members, reflecting their lived experiences, perspectives, priorities and ways of knowing, living and doing in Indigenous communities. Mostly, a community-based participatory research approach was employed to

conduct the research following the principle of OCAP® in the Canadian context to ensure data sovereignty.

4.2 Phase II- Focus Group Results

The second research question aimed at understanding the perspectives of health professionals on the aspects of assessing functional decline in dementia, especially IADLs, from informant information. I employed the focus group method following a community-based participatory approach. The establishment of the CAG, partnership with the Indigenous health organization, utilizing the concept of 4Rs throughout the research process, and following OCAP® principles to conduct this study have been described in the methodology chapters. In this section, I will describe the findings from the focus groups.

The health professionals involved in the focus groups were a diverse group of people with a range of personal and professional experiences in relation to the functional assessment of people with dementia. Two focus groups were conducted with the Indigenous and non-Indigenous professionals with distinct natures of dementia-related assessment and services. Besides health professionals, a few community members joined the focus groups. My partner organization, Maamwesying, partners with various communities between Sudbury and Sault Ste. Marie. To make it inclusive and accessible for the diverse participants to participate in the focus group, I conducted hybrid-style focus groups in two different places. A total of 17 individuals participated in the focus groups.

The first focus group was conducted in the Band Council Office of the Atikameksheng Anishnawbek community. Initially, eleven participants joined the focus

group, but one of the participants who joined online withdrew due to other commitments. Of the ten participants, two participated online. The participants in the focus group were a physician, an occupational therapist, a nurse practitioner, two nurses, a social worker, and a home care manager. Additionally, three of the participants were community members who were not health professionals. All participating health professionals were responsible for providing dementia-related and other health services to the people living in the Atikameksheng Anishnawbek community. The focus group was conducted for 90 minutes.

The second focus group was conducted with the Superior Family Health Team (SFHT) in Sault Ste. Marie. The focus group was conducted in the SFHT office in Sault Ste. Marie. Six participants attended the focus group. The participating individuals were the team responsible for providing dementia-related health and care services who consisted of the a nurse practitioner, two nurses, an Executive Director, a pharmacist and a program coordinator. The focus group lasted for 90 minutes and the food and coffee was provided and managed by the SFHT team as a support to Maamwesying.

4.2.1 Themes

The approach taken for this thematic analysis was inductive in nature shaped by the research question: What are the important aspects of functional assessment for dementia, especially IADLs, to be included in an informant-based tool for Indigenous populations? Qualitative thematic analysis led to the generation of five main themes and multiple subthemes. To my knowledge, this is the first study that aimed to understand the perspectives of health professionals regarding an Indigenous functional assessment tool. Thus, we covered

a wide range of topics such as the experiences of health professionals in relation to functional assessment, how the community people view dementia, experiences in using existing functional assessment tools, health professionals' experiences in relation to community people in regard to dementia assessment, and important approaches and domains to be included in the culturally appropriate functional assessment tool. The six main themes generated from the focus groups were (1) Indigenous perspectives on dementia, (2) Late diagnosis and disease progression, (3) Challenges faced by health professionals, (4) Barriers to accessing health services, (5) Approaches to potential Functional Assessment tool, and (6) Domains of new tools. The themes and their sub-themes are described in full detail below.

4.2.1.1 Theme 1. Indigenous Perspective on Dementia

The focus group participants highlighted that Indigenous People in this area of Northeastern Ontario, the Anishinaabek, perceive dementia as a normal part of aging. The changes resulting from the symptoms of dementia were considered a part of the circle of life, mostly going back to childhood as one was closer to the end of life.

“..... I know as well in the Indigenous culture, they do view like dementia as returning kind of to the youth, but that's not a bad thing, whereas, in Western culture, once you're not able to do things that tend to have more negative connotation(s). In that culture it's not, it's kind of just a circle of life or kind of like going back to childhood.”

(Health Professional 1)

The participants mentioned that the care preferences and the needs for dementia care and services of Indigenous people were different from those of non-Indigenous. Indigenous people mostly lived in multigenerational houses, and people with cognitive impairment and dementia often had someone available to support and take care of them. Family members or caregivers wanted to keep their loved ones at home rather than sending them to nursing homes. However, they required more help and support from health care providers and health systems. One of the reasons for not sending loved ones to institutionalized care was mistrust of the health system, resulting from the past experiences of racism and discrimination faced by Indigenous Peoples.

“I will say that most of the Indigenous families we’ve encountered have a different view of caring for their loved one. In this stage of dementia, whereas (in) different cultures, everybody looks secular in their own houses and you’re supporting from afar where a lot of times, they’re either living, multigenerational or they want to keep supporting in the home. So, it’s just in that way, it’s what their needs are different than other patients because your first option you know (is) to suggest a nursing home. You know that’s an institution, and that can be traumatizing, right. So, a lot of times that’s not their goal. Their goal is more to have more support in that to continue to care for their loved one at home. That’s the kind of the one difference I’ve noticed. It’s just getting enough help.”

(Health Professional 2)

4.2.1.2 Theme 2: Late Diagnosis and Disease Progression

Health Professionals mentioned that Indigenous people with cognitive and functional impairments were diagnosed at a later stage due to the tendency of families to provide care at home, which could delay the recognition of cognitive and functional decline. Family members or caregivers often noticed changes in behaviour and personality and memory loss.

Another reason for late diagnosis might have been that the family members have been considering the changes in cognitive, functional, and behavioural aspects as a normal part of aging.

“There's more family in there, kind of helping from afar as best they can, but then they will not- it's just in their culture that they don't put the minimum- they will keep them as long as possible care of their own..... I find mostly it's been later. We're not catching most of the cases we've encountered have been farther along.”

(Health Professional 1)

“We're community-based [service providers] so, a lot of them (individuals) do have primary care providers in their communities and once they are exhausted with what they're able to do to help, we get the referrals at that point. They're already up a bit further into (disease progression).”

(Health Professional 2)

4.2.1.3 Themes 3: Health Professionals' Challenges

4.2.1.3.1 Subtheme: Lack of Standardized and Validated Assessment Tools

Health professionals mentioned their dissatisfaction with using the existing assessment tools in the community. Without culturally appropriate, validated and relevant functional assessment tools, they used modified standardized and informal assessments for Indigenous patients. Such tools were hard to follow for Indigenous people, and, thus, they tended to score lower on the task. The language used in such tools was complex for families and loved ones to understand. Despite lower scores, the loved ones could continue to perform their IADLs. Sometimes, while conducting an informal assessment, health professionals relied on their intuition and changed the results obtained from the tool so that the loved ones

got the care they needed. Health professionals even mentioned the need for informant tools to provide better information about the functional capacity of an individual rather than assessing their ability.

“.....So maybe they may have scored very low on the assessment, but they're managing all those instrumental activities of daily living”.

(Health Professional 4)

Participants emphasized the importance of conducting separate sessions with caregivers or family members to obtain more accurate information regarding the functional capacity of their loved ones. They expressed discontentment with the existing assessment process, as sometimes patients overestimate their functional ability, which does not reflect reality. Thus, the discrepancy between the self-reported abilities of the individuals and their actual capabilities highlights the significance of gathering information from the family members or caregivers who may have a more accurate understanding of the individual's abilities.

“.....So, I think sometimes maybe even having like a separate session with the caregivers to get the actual true answers because I've gone in and done assessments and that person's answering yes, I do that. Yes, I do that. Yes, I do that. Yeah, I can do that. Yes, I do that. I do that all on my own and you know they don't. So, you're not getting that true answer.”

(Health Professional 3)

Some participants mentioned that sometimes they need to adjust the assessment results to ensure that patients receive appropriate care. They appreciate the chance to provide

personal comments while assessing the patients. Furthermore, they suggest separate sessions with the family member or caregiver to provide detailed information about their loved ones, which would help in more accurate and comprehensive assessments.

“For that assessment, when I go back to my office, I have to fudge those numbers so that they do get the care that they need. And you have the opportunity to put in your own comments, thank God. But often with family I think there needs to be some, if at all possible, like an opportunity tests questions aside or away from that person being assessed as well by the caregivers.”

(Health Professional 3)

Some participants mentioned that while they were not fond of using many assessment tools, they were optimistic about using some structured assessment tools. These tools provided a standardized way for health professionals to communicate about the results and the things to be concerned about with a dementia diagnosis. In addition, they always made an effort to support these scores with a practical observation of the loved ones' functional ability.

“I've never been a big fan of any screening tools to be totally honest, but in today's world, sometimes the score is a common way to talk with other health care professionals about like a result or what, where we might be concerned, but I always myself trying to back it up with what we're seeing functionally with the individual as well.”

(Health Professional 4)

Some participants were excited about developing a functional assessment tool in the context of Indigenous communities.

“I’m excited about the idea of having a more standardized approach to a functional assessment, which I think as OTs we try to do anyway, but it would be nice to give structure and have a common tool and have common language to talk to other health care professionals as well.”

(Health Professional 4)

When participants were asked about the appropriate assessment tool to assess functional decline in First Nations communities, they highlighted the lack of appropriate functional assessment tools, even for the general population. Rather than assessing the functional decline comprehensively, most existing tools merely observe and document the decline.

“No, not in my opinion. I think it's just basic observation and documentation, but yeah, even whether it's culturally sensitive or not, I don't think there's (a) great tool out there personally.”

(Health Professional 4)

4.2.1.3.2 Subtheme: Differences between Health Care Professionals

The participants explained that various health professionals provided dementia assessment and diagnosis, such as physicians, geriatricians, nurse practitioners and occupational therapists. Each of these professionals had their way of providing care to the patient, especially with dementia assessment and care. No standardized tools or guidelines existed to conduct such assessments and diagnoses, particularly for the Indigenous populations. In the same clinics, each health professional had a unique approach to diagnosing dementia.

“It's just, it's harder to make a bunch of different people who are all sharing space but practice different, do something similar. I'm not sure if it's like that in different health clinics.”

(Health Professional 1)

4.2.1.3.3 Subtheme: Time and Resource Constraints

Some participants mentioned that it was challenging for them to conduct a thorough functional assessment as they had constraints on their roles and responsibilities. Generally, physicians spent less time with patients as they were supposed to practice in a “time-efficient” fashion and had little control over patient scheduling. However, dementia assessment requires a lot of time with the individual, family member or caregiver along with the paperwork. In such a scenario, time constraints impeded the ability of the physicians to conduct the assessment thoroughly. Thus, when the physicians noticed some cognitive decline, they referred the patient to nurse practitioners or occupational therapists for thorough cognitive and functional assessment. The nurse practitioner and the occupational therapist who participated in the focus group mentioned that they were supposed to conduct the functional assessment thoroughly as they did not have time constraints. In addition, the nurses provided the informant assessment form to the caregiver and asked them to complete before visiting the nurse practitioners for an assessment of their loved ones.

“Some people want to know what's wrong, and they already have a sense that something's wrong. And they'll be open to the idea of having multiple tests done and actually, I tend to refer to an occupational therapist to do that because it's time-consuming and I have other medical stuff to do.”

(Health Professional 5)

“Our physicians come to our (memory clinic) team and tells us I have this patient. They send the patient to a memory clinic rather than investigating. I'm sure they do a little bit depending on the scenario.”

(Health Professional 1)

“So in that sense, if I give someone a tool, have them fill it out and then I review it after and ask questions based on their answers. Just time, like sometimes it's hard to go through. You don't have enough time in a 20-minute appointment.”

(Health Professional 1)

4.2.1.3.4 Subtheme: Challenges in Information Flow

One of the participants mentioned that some people with dementia moved away from their communities to access specialized care in other communities. In such a scenario, the health professionals were unable to access the individual's past medical records. The flow of information between the providers, especially when they moved between communities or locations, was challenging. The need for continuity in health system records and assessment resulted in such a challenge.

“.....what I see in practice is that when families start to see issues, they move the family member to another location/community where they will see new providers who won't necessarily have access to past medical records, treatments, etc. Even in the same community, they may have an outside provider with incomplete records..... And we don't have a good system in place by which to keep that information pool.”

(Health Professional 7)

When people with dementia were institutionalized in health care facilities from different communities, the health professionals did not know about the history of the patients.

It was challenging for health professionals to assess what had declined or changed with their function based on their earlier performances.

“...I think for me the history is what I see in our clients, it's very hard to know how they've declined when we don't even know the current baseline, or what they were before. So a lot of the things we kind of assume that oh, yeah, the person knows how to do their own banking. But I was thinking about this. And we actually have a lot of adults that don't do their own banking right now. But an agency or someone is actually helping them already. And then they become elderly or we start to notice (their) struggle. And then all of a sudden, you're saying, Oh, well, look, they can't even do their banking. They actually never did their banking, or they never cooked for themselves. Right. So I think that baseline kind of thing.”

(Health Professional 7)

4.2.1.3.5 Subtheme: Gap in Indigenous Knowledge and Safe Prompts

Some of the participants reflected the uncertainty and desire for guidance on cultural safety and potential harm while communicating with the patients. They acknowledged their lack of knowledge about culturally safe and harmful practices. Moreover, they expressed a need for feedback to better understand potential harm when interacting with people from different cultural backgrounds. This suggests an awareness of the importance of cultural sensitivity and a willingness to learn and improve their approach while communicating and engaging with patients.

“I guess for us, it's just we don't know what's culturally safe or harmful, right, so it would be nice to have feedback of what could potentially, you know, be harmful to ask.”

(Health Professional 1)

Most health professionals followed the assessment tool and assessed every patient similarly. The participants responded that if the tool was developed with culturally safe questions and prompts, it would be easier for them to conduct the assessment in a culturally safe way.

“So I do feel like we probably do it just the way we ask questions based on the person in front of us to whatever culture they are, but like again, it would be helpful if we had like specific prompts that were culturally safe.”

(Health Professional 1)

Some of the participants highlighted the need for training on cultural safety and sensitivity to ensure they accurately reflected the experiences of Indigenous communities.

“.....So I just definitely think that our team should have some of that training. And also just like if they're doing, you know, like tobacco is sacred, right? So then you go into like when you recommend quitting smoking and like knowing a bit more of how they view that and what to say about that, and you know things like that.”

(Health Professional 9)

4.2.1.3.6 Subtheme: Navigating Care Challenge

Some participants mentioned that sometimes individuals with early signs and symptoms of cognitive and functional decline resisted undergoing care assessments. Although health professionals were aware of the ongoing changes and the associated risks, people needed to discuss with health professionals what they were going through. This was quite challenging for health professionals working in the community as they could not provide care and services.

“For providing service, I connect with them (individuals) and ask if they’re open to it because a lot of times we have clients that will say no, they won’t let anyone in their home come in and assess or ask questions. So, sometimes we have people alone at home when they’re at risk. And they accept that they’re at risk and we have to just try to do our best to keep them safe even though we know that they’re not safe, especially if they’re alone and they’re going through dementia. Then it’s worrisome for us because we know they’re at risk but if that person is refusing all care, and assessments, how do you help them? So, it’s challenging sometimes.”

(Health Professional 3)

4.2.1.4 Theme 4: Barriers to Accessing Health Services

The focus group participants mentioned that Indigenous peoples faced barriers to accessing health care services. These barriers included geographical factors, travel difficulties, concerns and suspicions about how the health care professionals would receive them. Generally, older Indigenous people lived on reserve, and they travelled long distances to access dementia assessment and services, especially in the harsh winters of Northern Ontario. Thus, despite noticing early signs of cognitive complaints and difficulties in carrying out daily activities of daily living, family members and loved ones could not access the diagnosis and treatment in the early stages.

“...Sometimes it is expensive and difficult to get here. Because we’ve had patients come from like Blind River and that, you know, that’s a lot to get up to the Sault in the wintertime.”

(Health Professional 1)

Sometimes, patients had to travel to larger cities to get assessed in the absence of services in their community or nearby city.

“I have one patient, a person who was clearly having issues with memory and has early onset memory loss, and we didn’t have a clinic in Sudbury yet and had to go to Toronto to get assessed.”

(Health Professional 5)

Also, some participants explained that negative past experiences with health care providers were one of the common barriers that made Indigenous patients hesitant to seek medical care.

“So, I see that even in my own practice, I’ll see an Indigenous patient, and the first visit is very guarded, and they kind of want to see how I’m going to react or respond, and then I do find that once you build that trust, then the next point you do get quite a bit more information. Sometimes that and a lot of times they’ve told me that they’ve had very negative experiences in health care, right? They’ve been, you know, labelled or judged or just not listened to. So, they come very defensive or, you know, already feeling like I’m not going to help them.”

(Health Professional 1)

4.2.1.5 Theme 5: Approaches to Potential Functional Assessment

4.2.1.5.1 Subtheme: Multidisciplinary, Holistic, Flexible and Adaptable Questionnaire

The focus group participants mentioned that the multidisciplinary team of health professionals was involved in assessing dementia and providing care and services. Nurse practitioners and occupational therapists were directly involved in conducting functional assessments. The doctors, especially family physicians and geriatricians, conducted the initial assessment and referred to the nurse practitioners and occupational therapists for thorough assessments. Similarly, the role of personal support workers, client care coordinators and

pharmacists was enormous in identifying the decline in functional capacity and ability to perform activities such as cooking, cleaning, missing appointments, and picking up medications from the pharmacy in an individual with cognitive complaints.

“In some instances, there may not be a lot of family involvement. And then our PSWs are really imperative because they are the ones that are there every day, right?.... they are the ones that see and observe a lot of things. They know, clients, sometimes better than their own families.”

(Health Professional 4)

“Usually, when the personal support workers come back, and share that they start noticing things, then I will talk to (the) occupational therapist to go and assess for us.”

(Health Professional 3)

“So the things that I noticed is the family members mentioning the client care coordinators are really helpful as they know patients over a long period of time, and they (client care coordinators) mentioned people having problems coming into their appointments or they're missing coming into their bloodwork, just things like that. And then we go to the formal testing and occupational therapists tend to do all the work of figuring out what's the functional assessment, which is something you do in people's homes.”

(Health Professional 5)

“If the pharmacist contacts me and says this person is not remembering their medication, they think they've picked it up, but they haven't picked it up. That's a clue that something may be wrong. If the person repeatedly misses their appointments, those are all things that make me wonder what's happening.”

(Health Professional 5)

The discussion among the participants suggested a collaborative approach to the assessment process, with different professionals contributing, including physicians, nurse practitioners, nurses, occupational therapists and personal support workers.

Participants emphasized the importance of a holistic assessment approach, which considered not only cognitive and functional aspects but also spiritual, emotional, physical, and mental well-being. Some participants mentioned incorporating the Medicine Wheel framework into the assessment to address these holistic aspects.

“I know that I would want to be assessed on the Medicine Wheel. Or for it to be at least included in the assessment. Because I use that in my personal life. I know when I'm out of balance. And I'm out of balance at this moment... .. Anyways, I would like to see that incorporated, especially in our community; I think that a lot of us tend to go to those ways that if we don't really know about them, we can't really use them.”

(Health Professional 6)

“...Because it is holistic. And we're, you know, all your questions could be developed using all those quadrants so that you know, somebody isn't put off by a certain question because that is part of that tool. So, I don't know, I think that would be a good thing.”

(Health Professional 3)

Some participants mentioned that the tool should be flexible, with different options available for the health professional to choose depending on the beliefs and the history of the patients.

“The tool should be almost like an octopus. So you have different areas where you can go, depending on what they believe in, and what their past is. So that's how I feel about it. Shouldn't be really constricted and defined; it should be able to have tangents on it that you can take if you need to.”

(Health Professional 8)

“.....if some of those questions were assessing a certain kind of memory, there should be may be option one, two or three lock and you could pick what was suitable for that, sadly, but they would, as long as they will equally standardized and says maybe internally says.”

(Health Professional 5)

4.2.1.5.2 Subtheme: Collateral History

Collateral history refers to the information obtained from a suitable contact (friends, family or caregiver) about the cognitive and functional abilities of an individual. Health professionals discussed the importance of gathering collateral information from family members, caregivers, and PSWs who are familiar with the person being assessed. Collateral information provided a comprehensive detail of the functioning capabilities and limitations of an individual going through a cognitive decline. In some cases, when families were not available, PSWs were the ones to notice functional changes in the individual.

“I think I like two streams where you [health professional] are focused on the client and how they’re performing on the functional aspect of the assessment, but also the collateral. So, speaking with whether it’s the PSW, or the family member, to get that collateral picture as well, I think it should be a two phase not just solely focused on assessing the client.”

(Health Professional 4)

The focus group participants also highlighted the importance of having family members voice their concerns. When family members expressed worries or noticed changes

in their loved one's behaviour and their capacity to conduct everyday activities, it served as an early indicator of potential cognitive and functional issues.

"..... I would assess the patient if a family member mentions that there's concerns regarding memory."

(Health Professional 5)

"A lot of time (a) family member would give a lot of specifics about their loved ones but not want to say in front of their parents or their loved ones because they argue after and it makes their lives a little more difficult. So we get more about the IADLs and life at home from a separate interview (with family) than with them together."

(Health Professional 1)

Participants mentioned that all members of the family did not have an equal understanding of the ongoing changes in the daily activities of their loved ones. Some subtle changes in the early days were hard for any other member of the family to notice except those who interacted and lived with loved ones on a daily basis. Thus, it's crucial for health professionals to talk to family members who are close to their loved ones and have a better understanding of their daily activities from the past as well.

"Sometimes even the immediate family may not be too close to know the ongoing changes in their loved ones....sometimes the external family (son-in-law, daughter-in-law) have a different insight because they are not as emotionally attached and the person can be helpful to..."

(Health Professional 5)

"...but those are subtle things that (a) family notice, or, like, often a spouse will notice and the rest of the family says, oh, you're just getting older. But you have to listen to

themselves just like you listen to a parent of a baby. If the spouse says something's off, something is off."

(Health Professional 5)

Many participants mentioned that sometimes family members or individuals themselves may not have been open regarding the full extent of the patient's condition in front of the health professionals. In such conditions, health professionals needed to have separate sessions with the family members and the individuals with the cognitive and functional complaints.

"I think almost like you want family to be there with the person being assessed, but sometimes they're too anxious and they get too angry that those questions may not be answered correctly. So, I think sometimes maybe even having like a separate session with the caregivers to get the actual true answers because I've gone in and done assessments and that person's answering yes, I do that. Yes, I do that. Yes, I do that. Yeah, I can do that. Yes, I do that. I do that all on my own and you know they don't. So, you're not getting that true answer."

(Health Professional 3)

4.2.1.5.3 Subtheme: Engagement in Home Environment

The participants emphasized that an in-home assessment for functional decline helped health professionals better understand the individual's living environment, daily routine, and functional challenges. They believed that observing individuals in their natural surroundings provided a more accurate picture of their abilities and needs.

"that's a whole other, it's nice lot easier to see them in their own environment right to really pick up on, are they being able to keep up with maintaining the household. Are they.. Is there food? Are there, you know, stacks of bills that maybe aren't getting

paid on that? Yeah, so definitely gives you an easier perspective or window into that individual's life, for sure."

(Health Professional 4)

Some participants even mentioned that conducting an assessment in the home environment rather than a clinical setting created more comfortable and open settings for discussion.

".....if they're going into a clinic in Sudbury then they may be afraid they're not going back home if they don't answer right. So, the anxiety would be crazy high. So, I think in the home I agree with that as well and I don't know, I think almost like you want family to be there with the person being assessed, but sometimes they're too anxious and they get too angry that those questions may not be answered correctly."

(Health Professional 3)

Making it comfortable for the person being assessed or their family member is important.

Unless people were comfortable, they did not open up about their condition.

"I used to bring my dog in the home visits to try to keep clients calm and because it would make them happy or bring their mood up instead ofso they allow people in, I guess, to come visit them to try to ask questions. And then often if they would go but anyway but I don't know it's got to be different, done differently than it's done now. It doesn't work unless the person is open to it."

(Health Professional 3)

4.5.4 Subtheme: Storytelling and Open-ended Questionnaire

While conducting an assessment, health professionals needed to establish rapport with patients and caregivers, including asking questions related to the patient's life histories and hobbies. The techniques of encouraging patients and caregivers to share their stories

helped in identifying the difficulties faced by the individual in conducting everyday activities.

“I usually ask them, like you said, story time and ask them questions about their life or their family members, or like if they, especially when we're doing that initial part of you like, oh, what hobbies do you do and then they'll be asked some kind of specific questions just to develop like a rapport.”

(Health Professional 1)

Some of the participants emphasized the need for open-ended questions as this allowed for an exploration of an individual's unique experiences and cultural practices, rather than imposing a rigid questionnaire.

“....And they're very good at posing open-ended questions or follow up, and sometimes you have to build a rapport and sometimes you have to ask a question. I do find you have to ask maybe two or three different ways, if you're not getting the answer that you're looking for, but that I think comes with the experience of interviewing. So sometimes it takes a bit to pull it out, but you just may have to reframe or ask in a different way. But like I said, it would be helpful to have more, I think culturally sensitive options on our form to be able to pull that out.”

(Health Professional 1)

Some participants recommended that instead of a tool purely based on standardized questions and checklists, it should consider the subjective experiences and happiness of the individuals being assessed.

“And I think through the stories and questions that would get answered, using that tool that 're more open ended instead of just yes, no....I think it's so much from their story, like you'll get all the answers that we need through asking open questions

or open-end questions as I don't know if that's possible for an assessment tool....They don't like to be rushed or pushed or on a time limit. They just want to talk and share stories and so, I think this tool has to be something that's not certain, that here you go and talk to this person. It's only going to take you an hour, an hour and a half. You know, you have to be open to if it's going to take you a whole afternoon.

(Health Professional 3)

4.2.1.5.5 Subtheme: Tailoring Health Care Tools

Some participants explained the generalization of Indigenous people. Although Indigenous people were diverse in terms of language, traditions and geography, it was generalized that Indigenous people followed similar cultures and traditions, which may not always have been true. The participants cautioned that while assessing the patients, health professionals needed to put away their biases of generalizing Indigenous people in the same manner. With the diversity in language, culture, beliefs, values and ways of living among Indigenous communities, it was harder for health professionals to find ways of assessing the individual for dementia.

“And I agree with the comment, somebody said like, just the variation I think we're very quick to generalize oh, First Nation. Even amongst our eight or 10 sites here the communities are very different and that so yes, they're all Annishnabewk but each community has a different flavour aspect....But like she (another participant) mentioned there within the community, you have the rules that are, let's say traditional, practice a lot of traditional ways traditional medicine, we have some that kind of smudge or maybe you use a little that or that. And then we have ones that say no, that's, that's crazy, I don't do any of that, right? So I think it's very, it's very tempting to generalize, but I don't think you can generalize. And that so that makes it tough part of the assessment tool.”

(Health Professional 7)

Health professionals emphasized it was essential to tailor assessment tools to meet the specific needs and cultural backgrounds of the individual patients. Indigenous communities were diverse regarding cultural practices, beliefs, and experiences, making a one-size-fits approach ineffective. Even more, Indigenous communities varied by language, traditions and geographical contexts. Assuming that Indigenous peoples embraced traditional paths may have been true only sometimes. Thus, health professionals should be cautious about bringing preconceived frames of reference when assessing loved ones. Health professionals often faced challenges when determining the appropriate methods of assessment within Indigenous communities residing in the same geographical area due to variations in beliefs and way of life.

“I wish the tool could be flexible. So, when you talk about cultural sensitivity and safety and creating those aspects of the tool, everybody is individual so some of my clients are very, very much do a lot of ceremony as well and they like to do their smudging, participate in other ceremonies and very apparent in their home so that would be a part of their functional assessment. Some of my other clients do not, so one size fits all, whether it's I don't know, if there really is like, I want something that's adaptable.”

(Health Professional 4)

"And I'm just wondering if not everybody in our community is traditional. So, you know, you would have to kind of weigh those factors to see, what is the best way to assess."

(Health Professional 6)

Participants also emphasized the need for brief, quick, precise screening questions that could be easily administered by health professionals. Longer surveys or assessments might not have been as effective as they can be burdensome to both health professionals and family members or caregivers. Thus, they suggested that developing pre-screening questions

might help them to rule out the signs and symptoms and help make decisions for detailed functional assessment.

“So I think like a few quick screener questions that look at that change in impairment of memory. And I think two questions that ask about short-term memory changes, because those are typically for, if you're looking at the dementia it's that they have you know, subject you're looking for that memory loss.”

(Health Professional 1)

“Like nobody wants to do little surveys, right? And it's kind of like a survey. I think about anything more than three (questions) and like forget it, I'm not going to do it....Put something short to keep there.”

(Health Professional 9)

4.2.1.5.6 Subtheme: Early Assessment and Baseline Information

Participants highlighted that it was essential to ask the family members or caregivers about the abilities, interests and daily activities of the loved ones before cognitive decline appeared. While assessing loved ones, health professionals wanted to understand the differences from a year ago to now, basically what they could not do in the present context that they used to do. Loved ones did not necessarily perform all the tasks mentioned in the assessment tool prior to their cognitive impairment, and assuming otherwise could lead to inaccurate assessment. Thus, it was crucial to know the baseline of the loved ones from the family members before reaching a conclusion.

“I'm terrible at doing that, you know, when I sit down with somebody, when I first meet them, I don't ask you, do you like reading? What are your hobbies? What are the things that you do for fun? And that those would be really good questions to ask.”

Because then if later there's a problem, you can say, Oh, are you still doing your whatever? And if they say no, you can ask them why? And maybe they say, sometimes they had said to me, it's just getting too hard, or I don't read anymore. Don't make any reading. That's a clue that something's wrong. So that's helpful... ”

(Health Professional 5)

“...it's what can they not do now that they could do before because of their memory right, that's when you're if you're going to count an IADL as impaired cause. If they never did their taxes, that's not an impair (ment) they just never did it. So, that's biggest thing to tease out from caregivers is what activities or what things in their life that they use lots of brain function for can they not do now that they could do a year ago or before. And it's because of their memory. It's not because they physically, (you know), they have arthritis and now they can't knit, is they can't knit because they are mixing up the pattern and the counts. And they used to knit beautiful Afghans and now there's holes and they can't finish the project. Same with like the beading like ok, they used to be beautiful jewelry. Now they don't know how to, you know, work the equipment.”

(Health Professional 1)

Some participants suggested that asking individuals or family members about their hobbies and interests that could be related to cultural practices could be valuable. Changes in these activities might serve as early indicators of cognitive and functional impairment.

“Like the game or skill or hobby like you could be maybe more specific on like any type of skills or hobbies that would be within their culture. I feel like that one it does.”

(Health Professional 1)

“So in each category that gives us examples of the being able to accurately do the IADLs, like the hobbies, doing a computer tools, instruction, skill, games, TV. So again, you could maybe have more culturally you know, appropriate examples.”

(Health Professional 1)

4.2.1.6 Theme 6: Domains

During both focus groups, some participants mentioned specific domains of IADLs that must be incorporated into the functional assessment tool. The domains that repeatedly surfaced during the discussions were loved ones needing to pick up or refill their medication from the pharmacist, missing doses of the prescribed medication, and missing blood tests or appointments with health professionals.

“Alright, another thing that our pharmacist will do is to see if there's an impairment in taking the medication in (the) correct way.”

(Health Professional 1)

Besides these, participants reflected on the deep-rooted connections of the community members with the land. They emphasized that almost everyone in the community has some form of connections to the land, whether through ceremonial practices, engaging in maple syrup, hiking or simply driving through the bush. Some participants mentioned activities such as going out to the sugarbush with either the community or the families, indicating a connection to traditional practices and communal activities. Furthermore, engaging in activities such as participating in smudges, playing bingo, or doing craftwork, fishing and hunting also contribute to fostering cognitive skills and cultural engagement within the community. Such activities could be potential domains to assess the functional abilities of the people living in the community.

“Maple syrup is one that will still do. And you know go out to the sugarbush with the community or with their families.”

(Elder 1)

“I think almost everybody in the communities have some kind of connection to the land. You know, whether it's through ceremony, whether it's through maple syrup or different activities, hiking or someone's just going for a drive in the bush. And if you drive them through the bush or into the bush, you feel all that stress just going away. So, they look more than just that ride in the bush even if they can't walk anymore. But it's still that connection...”

(Health Professional 3)

“And same with like the understanding TV show, book or magazine like that's all kind of more literacy stuff like that could be you know, are they following, you know, when they're like in there when they're doing the smudges or they're following along with. Bingo or even just craft like cracking and, you know, crafts, lot of beadworks.”

(Health Professional 1)

4.2.2 Summary

The focus group result section examined, in detail, the perspectives of health professionals on the Indigenous functional assessment tool. It offered a nuanced analysis of the experiences of health professionals in assessing functional aspects of dementia within the First Nations population. The findings revealed that health professionals faced several challenges, including the lack of standardized and validated assessment tools, variations in dementia assessment among health professionals, as well as time and resource constraints. Additionally, there was a gap in knowledge regarding Indigenous cultural aspects and appropriate prompts for assessment among health professionals. Even the loved ones, their families and caregivers faced several barriers while accessing dementia assessment and care services. To address these challenges, health professionals discussed potential approaches to

developing a culturally relevant and appropriate functional assessment tool. Those approaches included multidisciplinary, holistic, flexible and adaptable questionnaires; detailed history from the family members or caregivers, creating comfortable and safer spaces for loved ones and their families, and incorporating storytelling and open-ended questions. The focus group highlighted the need for tailoring health assessment tools as the Indigenous communities are diverse in terms of language, traditions and geography, as a one-size-fits-all approach is inadequate. Moreover, baseline information in regard to the daily activities of loved ones is needed as the functional domain assessed by the health professionals may not be relevant in that individual's context. Finally, the questions related to hobbies, cultural ceremonies, medications, and appointments are some of the important domains to be included in the newly developed functional assessment tool

Chapter 5

5. Discussion and Conclusion

This chapter discusses the findings from the scoping review and the focus groups about the perspectives of health professionals on the Indigenous functional assessment, personal reflections and the growth that evolved from the research process, as well as considerations of the implication for practice and future research. The first phase of the study included a scoping review aimed to identify approaches and methods used in informing the adaptation and development of health assessment tools used for Indigenous populations across Canada, USA, Australia and Aotearoa/New Zealand. The second phase consisted of a preliminary community-based study to inform the development of an Indigenous functional dementia assessment tool.

5.1 Key Findings and Contribution to Literature

5.1.1 Key Findings- Scoping Review

This scoping review sought to characterize the approaches and methods used to translate, adapt or develop a health assessment tool for Indigenous populations across Australia, Aotearoa/New Zealand, Canada and the USA. Overall, most tools are adapted or developed for the Indigenous population in Australia, followed by Canada and USA, and Aotearoa/New Zealand. One-third of the tools were developed to assess health and well-being in Indigenous populations of different age groups, children, youths and adults. Mental

health, alcohol and drug use were other categories where most tools were adapted or developed. Some tools developed specifically for the Indigenous context using Indigenous frameworks considered looking into the holistic approach to health rather than focusing on addressing a specific problem or health condition at a time.

Of the 36 studies, the majority (n= 29) were published after 2010 (Figure 4). It may be possible that studies only increased in appearance after 2010 as the issue of Indigenous Peoples's health and rights gained worldwide attention after the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the General Assembly in 2007. The UNDRIP initiative raised the need for countries to not only recognize health disparities faced by Indigenous Peoples worldwide but also to respond with an appropriate mode of action (Wali et al., 2021). Earlier, Australia, Aotearoa/New Zealand, Canada and the United States were against UNDRIP (Wiessner, 2010). Three of these countries voted to support UNDRIP in 2010 (APF & OHCHR, 2013), while Canada officially adopted and promised to support UNDRIP only in late 2015 (An Act Respecting the United Nations Declaration on the Rights of Indigenous Peoples, 2021). The results of this scoping review coincided with the unfolding of these events as the most common study locations were Australia (n = 24) followed by Canada (n = 6), the United States (n = 3) and Aotearoa/New Zealand (n = 3). Furthermore, the rise in research from Indigenous perspectives over the years can be credited to the substantial growth in Indigenous leadership within the field of health research and the integration of Indigenous worldviews and ways of knowing (White et al., 2021).

Due to the absence of health assessment tools explicitly developed for Indigenous people, cross-cultural adaptations have been carried out to modify existing tools to improve their acceptability and suitability for use in Indigenous populations. Tools that were adapted to the Indigenous context underwent the formal process of cultural adaptation following recognized guidelines to make their use meaningful and acceptable in Indigenous populations (Le Grande et al., 2017). An example of how the existing concepts from the dominant culture were adapted in the Indigenous context is the adaptation of the *Patient Health Questionnaire-9* (PHQ-9). In this qualitative study, Brown et al. (2013) defined the concept of depression in Indigenous men, thereby disregarding the Western concept of depression.

Indigenous approaches and methods in adapting and developing tools have advanced over the years. My scoping review showed that the majority of the instruments in the review were developed specifically for the Indigenous context and used various Indigenous approaches and methodologies in the process of development. With the exceptions of data collection or tool-reviewing, the tools that were adapted or developed earlier were modified or developed with expert-driven approaches without considering the community's involvement (Almeida et al., 2014; Amberber, 2011; Benn et al., 2021; Ching, Hou, et al., 2020; Ching, Saetre-Turner, et al., 2020; Dionne et al., 2014; J. P. Fitzpatrick et al., 2013; Palmer, 2004; Schlesinger et al., 2007; Vindigni et al., 2004). The experts developed most of the items or content using a literature review followed by consultation with Indigenous community members and health professionals (Almeida et al., 2014; Benn et al., 2021; Ching, Saetre-Turner, et al., 2020; J. P. Fitzpatrick et al., 2013; Palmer, 2004; K. Smith et al., 2016; Stewart & Gardner, 2015; Vindigni et al., 2004). Gradually, researchers formed

Indigenous reference groups or advisory committees, which guided the research process (A. Brown et al., 2016; Janca et al., 2015; LoGiudice et al., 2006b). This depicts the gradual shift of the dominance of Western constructs in tool adaptation and development processes towards Indigenous methodologies and methods and privileged Indigenous voices (Kennedy et al., 2022).

In recent years, Indigenous research methods such as yarning (Kennedy et al., 2022) and photovoice (Anderson, 2023) are being used to understand the lived experiences of the community people through their stories. Yarning is frequently used as a way of decolonizing research practices that privilege Indigenous ontologies (Kennedy et al., 2022). Some authors in the scoping review have used yarning to understand the lived experiences of the community people (Butten et al., 2021; Janca et al., 2015; Kotz et al., 2016; Marley et al., 2017). Apart from yarning, some researchers used photovoice, whereas others adjusted the long-established academic research methods such as focus groups and in-depth interviews in the Indigenous context. As a best practice for research involving Indigenous peoples, the research should aim to follow the ethical guidelines, protocols, and processes established by the specific community involved (Hayward et al., 2021); however, most of the articles in the review did not mention following standard community protocols. Only studies from Canada explicitly described following community protocols and also those communities had their own research ethics board (Gomez Cardona et al., 2021; Jacklin et al., 2020b; Young et al., 2013). Kovach recommends that research with Indigenous peoples is meant to be ethical, epistemological, and methodological inclusion of voice, and understanding and practices of Indigenous people (Kovach, 2021).

Indigenous health research is meant to be community-driven; however, in some tool adaptation and development processes, the questionnaires were developed by experts and community involvement was limited to data collection and refinement of questions to ensure cultural appropriateness. Unless the community is involved in the entire process of determining the research idea, objective, methodology, data collection, data analysis and dissemination of the study results, it will increase the risk of tokenism in Indigenous health research. Tokenism refers to a situation where Indigenous people or communities are involved in research primarily for symbolic representation rather than meaningful engagements (Baydala et al., 2009). There should be the meaningful participation of Indigenous communities in the whole research process (Hyett et al., 2018).

Through translation and adaptation, tools underwent rigorous cultural adaptation and clinical validation. Most of the tools were produced as a part of a larger project designed for the specific Indigenous population. Some of the articles in the review addressed the validation of the tool but did not provide many details about the tool adaption or development process. Given that the tools developed in one Indigenous context are being culturally adapted in another, it is a process of building upon, rather than breaking down, the work done by others. This is one of the successful steps towards sovereignty and self-determination by learning from each other's experiences.

Apart from discussing the methods used in the tool translation, adaptation and development process, I used a common framework that utilizes the concepts of respect, relevance, responsibility and reciprocity (4Rs) to synthesize the results. Given that Australia, Aotearoa/New Zealand, Canada and the United States have their own set of guidelines for

conducting Indigenous health research, the concepts of the 4Rs are directly or indirectly applied to the research protocols and ethical guidelines. Some of the prominent organizations following the Indigenous protocols and ethical guidelines in these countries are the Australian Institute of Aboriginal and Torres Strait Islander Studies (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020), the Canadian Institutes of Health Research Guideline for Health Research Involving Aboriginal People (CIHR, 2013), the Ethical Research Involving American Indian/Alaska Native Populations (Sahota, 2007) and the Te Ara Tika Guidelines for Māori research ethics (Hudson et al., 2010).

This scoping review suggested that researchers have made efforts to follow the concepts of respect, relevance, responsibility and reciprocity while adapting or developing assessment tools to some extent. Partnership with the communities as a responsibility of the researcher shifts the research priorities towards issues that are meaningful to the community and this shift will enhance the social and contextual validity of the study (Hyett et al., 2018). The community-based participatory approach further indigenizes the research process, providing power and control over the research, which will privilege and validate Indigenous narratives and systems (Peters & Peterson, 2019b).

My scoping review suggested that relationships were built with communities in several ways. Some research was grounded in existing community relationships or longstanding partnerships built over several years, and others were built on new relationships facilitated through community visits before initiating the research. Relationship building was reported as a formalized process, whereby a community oversight body (e.g. a community advisory committee, steering committee, working group) was created to direct the research

and was achieved through informal moments, such as researchers participating in community events and celebrations.

Although many of the articles did not mention how they built the relationship with the communities, the essence of the papers leads us to believe that there was some relationship built between the community and the researchers. However, (Murphy et al., 2021) warned that explaining the process of relationship building in a research paper does not guarantee that the researcher is being accountable or reciprocal or indicate the success of the project from community's perspective. All studies reported engagement with communities or community members at some point, but the extent of involvement varied among studies. While using the 4R concepts in analyzing the tools, there are many overlaps among the 4R concepts. As the concepts of 4R are interdependent and not mutually exclusive, it is challenging to exclusively categorize Indigenous health research's content in respect, relevance, responsibility and reciprocity.

5.1.2 Key Findings- Focus Group Discussion

To the best of my knowledge, this is the first study to understand health professionals' perspectives regarding culturally grounded and appropriate functional tools for dementia functional assessment. This study focused on identifying the perception of health professionals who assess dementia and provide care and services regarding the existing tools, challenges faced, and approaches and domains required to develop culturally appropriate functional assessment tools for the community. The study participants reported that Indigenous peoples generally access dementia assessment, diagnosis and care at the later

stages of the disease progression due, in part, to the belief that the signs and symptoms of dementia are a normal part of aging. Family members or caregivers provide care for their loved ones at home as long as they can seek help from health professionals when they can no longer do it on their own. In a study by Jacklin & Pitawanakwat (2019), dementia in Indigenous communities is experienced more gently, and the illness and its symptoms are greatly accepted.

In my study, health professionals discussed several challenges they experienced while providing dementia assessment, diagnosis and care. Such challenges included a lack of standardized and validated functional assessment tools in an Indigenous context, lack of consistency and guidance around appropriate functional assessment methods, diverse Indigenous communities, time and resource constraints, lack of integrated health system records, and gaps in Indigenous culture and activities-related knowledge. Lack of confidence (Bryant et al., 2021) and Indigenous-specific cultural safety education and training (Chakanyuka et al., 2022) were other forms of barriers faced by health professionals. Participants mentioned that different health professionals across the communities used various functional assessment tools they were familiar with to be able to assess the validity of the results. As a result, there is a lack of consistency and guidance around appropriate functional testing methods for use with Indigenous populations in communities. Similarly, in Indigenous Australians, in the absence of appropriate standardized cognitive assessments, clinicians often used informal methods for assessing cognition or relied on mainstream standardized tests that they had adopted or were familiar with (Dingwall et al., 2013b). Participants in this study pointed out that, in the absence of integrated health systems, health

professionals providing dementia assessment, diagnosis, and care to patients from different communities are unaware of the patient's history. Integrated health systems help to collaborate better and share information among health professionals, providing updated information about the history and service accessed by the patient (Leatt & Guerriere, 2000).

In addition to challenges faced by health professionals, participants mentioned that families and their loved ones experienced multiple barriers in seeking dementia assessment, diagnosis and care. They usually travelled long distances to access health services, even during the harsh winters. This is particularly true for Indigenous older adults living in rural and remote areas, where access to health care services and programs is limited. Accessing services beyond primary care often requires travelling to urban centres, causing significant disruption to their lives and those of their families has been reported in other studies (Davy et al., 2016; Halseth, 2018a; National Collaborating Centre for Indigenous Health, 2011). Moreover, participants reported that Indigenous peoples often approached health services with suspicion, concerned about how health professionals would receive them. Indigenous people often fear, distrust and lack willingness to engage in Western health systems and professionals due to their past experiences with racism and discrimination within the health care system (Halseth, 2018a; Pilarinos et al., 2023).

The results from the study highlighted a higher degree of diversity among Indigenous cultures, peoples, and languages within communities. Thus, the health professionals suggested tailoring assessment tools according to the community's needs. Similarly, in a qualitative study among health professionals regarding a diagnosis of dementia in Australian Indigenous, health professionals mentioned that using tailored, pictorial, visual or

photographic resources was beneficial (Bryant et al., 2021). Dingwall et al. (2013) also emphasized the importance of tailored assessments for Indigenous communities. Non-Indigenous health professionals noted that they are equipped with limited cultural understanding of Indigenous peoples and acknowledged that they require training on cultural awareness. Cultural awareness training helps health professionals engage in self-reflection and develop practical solutions for better handling of cross-cultural clinical situations, eventually leading to culturally safe care (Kerrigan et al., 2020).

The results from the focus group suggested that the potential functional assessment tool should be multidisciplinary, adaptable, flexible and consider a holistic understanding of health. Participants mentioned that family physicians, geriatricians, nurse practitioners, occupational therapists, nurses, pharmacists, personal support workers and client coordinators were involved in various capacities in assessing dementia. Others have discussed the importance of collaboration among multi-disciplinary health professionals that supports creating care pathways by delivering integrated health care to patients, families and communities (Bryant et al., 2021; Galvin et al., 2014). This study highlighted the importance of collateral history from the family, caregiver or personal support worker in case the family is unavailable or involved in functional assessment. Fitzpatrick et al. (2020) also reported that while people with cognitive and functional impairments cannot provide information regarding the changes in their cognition and the effects of those changes that interfere with everyday activities of daily living, collateral information is essential in accurately identifying dementia and planning appropriate treatment. Some participants mentioned during the focus group that, due to time constraints, they provided some assessment questions to the family to

fill out while waiting for the health professionals. Diverse information on performance, provided by informants and in self-reports, some of which can be completed in the waiting room or by non-physician staff before the start of the office visit, could help inform the presence or absence of disorder, identify the extent of disorder and help develop a differential diagnosis and management plan (Galvin, 2018).

The focus group participants emphasized that health professionals conducting assessments should carry out assessments in a quiet, relaxed and positive environment and let participants share stories about home and family life. Participants even highlighted the importance of storytelling. While the family members shared the stories of their loved ones, important details about their cognitive and functional abilities were shared during the conversation. Other studies support professionals provide space to make families and caregivers comfortable expressing their emotions by showing empathy, processing emotions, and listening to their stories (Thoft et al., 2021). Conducting an assessment in a comfortable setting, identifying common connections and humour and investing sufficient time to develop rapport, trust, and engagement are essential for health professionals (Dingwall et al., 2013b). Some participants shared that building rapport with the families or caregivers was important as families provided key information to the health professionals. Sometimes, family members could not share the information when they were with loved ones but shared it through the telephone or at separate sessions. The focus group findings revealed the developed assessment instrument should be brief, portable, engaging, and performance-based, and emphasized having flexible and adaptable tools to address the community's diverse needs. Others have commented that existing instruments lack the flexibility or broad

scope to consider individual and contextual factors in the assessment (Pennington et al., 2018). Without baseline information about the cognitive and functional capacity of the loved ones, health professionals cannot understand the changes that occurred in the cognitive and functional capacity (Galvin & Sadowsky, 2012). Thus, the future tools need to have questions related to the baseline regarding the functional capacity of loved ones. Finally, in this study, the importance of tailoring functional assessment to the individual was emphasized.

5.1.3 Critical Reflection of the Research

Colonization and ongoing colonial systems continue to negatively impact the health and well-being of Indigenous Peoples, contributing to a higher risk of dementia (R. Henderson et al., 2024). Indigenous populations have been forcibly removed from their ancestral land, disrupting their traditional way of life and access to natural resources essential for their health and well-being (Ninomiya et al., 2023). Similarly, colonial practices have tried to suppress Indigenous languages, traditions and knowledge systems, leading to the loss of cultural identity and increasing the vulnerability to conditions like dementia. In addition, other key determinants such as socio-economic status, systemic racism, cultural perspectives and practices, health care access and safety influence the health of Indigenous people (R. Henderson et al., 2024).

Dementia is seen to be relatively new to Indigenous communities. The existing approach to assessing cognition and function to diagnose dementia uses a biomedical model. This has created challenges for evaluating dementia for Indigenous people in a culturally

relevant and safer way. The use of assessment tools in the Indigenous context, without considering the cultural differences, can lead to the inappropriate application of normative data and inaccurate or biased diagnosis of dementia (Acevedo-Polakovich et al., 2007). This further perpetuates the marginalization of Indigenous people and results in inadequate treatment and access to appropriate and culturally relevant health services (Sharma et al., 2024).

A growing body of literature shows that assessment tools are influenced by cultural, social and ethical values and carry inherent biases that may harm Indigenous populations by not considering their unique cultural contexts and perspectives (Gale et al., 2022). For years, clinicians conducting assessments have been trained in conventional expert-centric approaches and struggled to accept that patients know best what helps and harms them. However, evidence supports the importance of incorporating patients' experiences in assessing the efficacy of the treatment or intervention. Similarly, expert-centric approaches have been the reality of the tool development and adaptation process, which is gradually changing with Indigenous approaches and methods that emphasize engaging with the Elders, community members and Indigenous councils rather than solely with clinicians and experts in the field. This has been supported by the scoping review results where 23 out of 30 tools consulted with communities to various extents. Before researchers adapt and develop assessment tools in Indigenous contexts, there is still a long way to go. In addition, the scoping review reported that significantly few assessment tools were consistent with Indigenous worldviews and holistic character of complete well-being.

Henderson (2000) describes that Indigenous worldviews are considered to be inferior and inadequate, both explicitly and implicitly, as compared to Eurocentric worldviews. In addition, a negative image was developed by Eurocentrism towards diverse Indigenous worldviews that were extremely destructive to Indigenous languages, knowledge and existence and stripped the knowledge, dignity and wealth of Indigenous Peoples. Indigenous Peoples have been assimilated into the Eurocentric values through policies such as residential schools and the sixties scoop. Henderson further explains that the Eurocentric system established cognitive and physical modern boundaries of imprisonment for Indigenous Peoples to maintain their enormous privileges and enslaving visions. The cognitive boundaries were established by dismissing or denying the holistic knowledge and thought of Indigenous people. Moreover, Eurocentric education forced Indigenous Peoples to live according to imposed Eurocentric scripts, which led Indigenous people's educational and professional experiences to be disconnected from their worldviews, languages and teachings. Besides the loss of languages and cultural teachings, through assimilation of the Eurocentric beliefs and values, Indigenous people were forced to accept the Eurocentric educational system as an unalterable face of life (J. S. Y. Henderson, 2000).

Standard psychometric properties consist of determining the tool's reliability and validity, which provides information about its adequacy, relevance and usefulness (Solomon Chukwu Ohiri & Nnennaya, 2024). In general, the existing tools developed for assessing cognition and function for dementia diagnosis overlook the complete and dynamic contexts of the individual, focusing instead on the physical aspect. It ignores the rich description of the person's lifeworld, home, community, and historical, social, political and economic

contexts, which impact the person in totality (Gale et al., 2022). Thus, there are always two competing ideas. One is that isolating the individual from various outside factors gives more control and accurate measurement. Another aligns with Indigenous perspectives that to understand a person in total, one needs to consider the context. Indigenous epistemology rejects approaches that see a person in a one-dimensional way, such as specific test results (Gale et al., 2022).

Thus, shifting the development of the tool in the Indigenous context merely focusing on the psychometric properties towards considering the totality of an individual and their relationship with their family, communities, and surroundings is needed. The results from the scoping review and the focus groups with the health professionals from this study also focused on relational accountability while developing the tool. It's time for researchers and clinicians to shift their focus from merely psychometric properties and performance on a standardized test to an individual's relationships. This research supported the idea that besides the tool's psychometric properties, the tool development process should consider the relationship of the family members with their loved ones and how the family members conceptualize the cognitive and functional changes in their loved ones. The most important consideration is how Indigenous people view the construct of function. In this research, I tried to define the construct of function from health professionals' perspectives. The next step needed to move forward with this work will be to understand the construct of function from Indigenous caregiver/family member's perspectives. This research also reported that health professionals were building relationships with loved ones, making them comfortable for assessment, and striving towards equalization of power to reduce the mistrust and

discrimination faced by the Indigenous people while seeking healthcare services. As standardized tests risk the decline of relationships with the patients and prioritize speed over care, health professionals who were using these tools also took time to listen to the stories of the patients, making sure that patients felt safe, respected and valued. The research participants recognized the diversity of Indigenous communities and recommended tailoring the tool to meet each community's needs. This raises the question of how to balance the standardized norms and scoring employed by the system with the need for customization for different Indigenous communities and populations. To date, tools that compare to standard norms from other populations have been applied in the Indigenous context, but these existing tools have failed to diagnose dementia in a timely and appropriate manner (Bryant et al., 2021). We need to understand the different perspectives of communities and how they perceive this concern. To develop the tailored tools for various communities, we need to collaborate with them, ensuring that the underlying measurement remains consistent, even if the questions are adapted to be language or culture-specific. It's simply a matter of applying these measures in a way that respects and reflects each community's unique context.

The larger objective of developing a culturally appropriate functional assessment tool was to recognize barriers between the researcher involved in creating the tool, the health professional using the tool for assessment, and the community people for whom this tool was being developed. Engagement of the researcher with the health professionals, community partners and the community people was meant to minimize the potential harms arising from the inherent power imbalance through decolonizing, being aware of differences, considering

power relationships, implementing reflective practice during the tool development process and allowing the community to determine whether the use of the tool is safe.

5.1.4 Self-reflection

I used Wilson's Indigenous Research Paradigm as a theoretical framework for my study. As I am not Indigenous, I acknowledge that I cannot think and reflect from the Indigenous perspective as an Indigenous person. I knew that for this research to follow Indigenous perspectives and Indigenous ways of knowing, I had to commit myself to practicing relationality. This meant practicing what I had been reading about, including truthfulness, trust, respect, responsibility and reciprocity. Only from a space of openness and sharing would an honest exchange be possible. I hope that this research has, to some extent, contributed to co-create new insights concerning the use of Indigenous knowledge systems, methodologies, and research positionality. For myself, the whole research process has helped me to get out of a sense of doubt that, being a non-Indigenous person, I would be able to justify doing Indigenous research. But I can assure you that the relationship and the trust I have built over the years with my community partner, Elder, CAG, and support from the Elders in the community reflect that I am moving on the right path. I have a long way to go, but I feel like I have started it in a good way. While writing about my reflections in different chapters, my eyes were filled with tears. I felt these tears as a sense of fulfillment and accomplishment. Being trained in a Western academic setting for most of my life, I never thought I would write my emotions and thoughts on my thesis to be read by people.

I started this thesis by introducing myself, my worldviews and my relationship to the place, people, ideas and cosmos that inform my perspectives. In an earlier section, I mentioned how I came across the research topic, and the methods and methodology used in the research process. I formed a relationship with Maamwesying North Shore Community Health Services during the COVID-19 pandemic. Due to the restriction in place, my first CAG meeting was held online, and I could not offer tobacco to the Elder in my committee as considered a “good way” to start the research process. However, I sent some gifts to Elder from Nepal, along with the agenda for the meeting and the Terms of reference for the CAG. The meeting started with the prayers, and I introduced myself and the objectives and motivation behind the work. The Elder and other members gladly accepted to be in the CAG. One of my CAG members told me to treat my project as a living entity. The Elder agreed to guide this project with her wisdom. The research methods underwent various trial and error. In addition to CAG and Maamwesying, my Ph.D. Supervisory Committee greatly supported me and guided me to conduct the preliminary study to inform the development of the tool rather than doing the whole process of developing a tool. At first, I was disappointed as I felt my research scope was reduced, but Maamwesying agreed to assume the work of developing the tool once I completed the preliminary study. Now I can be assured that the work I am a part of will one day be used for the betterment of the lives of people living with dementia.

During this journey of Ph.D., I presented my research topic on various platforms, to various communities, health directors of Indigenous health organizations, conferences, and health professionals, and all those discussions and feedback were part of my learning process. I can assure you that I followed, as per my understanding, the concepts of respect,

relevance, responsibility, and reciprocity in every stage of the research process. I remember when I presented my research objective to the Senior PAC, one of the Elders called me, held my hands and prayed for me that the work that I had started would be done successfully. During that moment I felt like for all these years, I had been waiting for that moment, and that was my biggest accomplishment. Although I was not able to start my research process by offering tobacco to Elder, I wanted to close my work by offering tobacco to Elder. I tied the tobacco, thinking of my work and offered it to Elder the next day. I cooked some of my Nepali food and packed some of the gifts from Nepal and the honorarium. I updated her about my project, gifted her and saw how she was interested in tasting the food I made for her. Earlier, I was confused about what I should make as I am not good at making Western food, but I cook traditional Nepali food every day for my son. Then I realized that I needed to be myself and cook Nepali food. My joy was unlimited. I felt like all these years I spent time making relationships came to fruition.

Wilson describes research as a ceremony of maintaining accountability to relationships. He emphasizes that we must be accountable for all our relations by carefully choosing our topics, data collection methods, forms of analysis, and the way we present formation. In the above sections, I described these processes in detail. Indigenous research as a ceremony is a relational, holistic and respectful approach to knowledge creation and sharing. The concept of ceremony treats research as a sacred process embodying the principles and values of Indigenous culture that honours the interconnectedness of all life. I tried to follow the principles of respect, reciprocity, responsibility and relevance throughout the research process. I approached this research holistically, aiming to understand the

phenomena in their entirety rather than in isolation. The partnership with the Maamwesying and the relationship built with the CAG and SPAC were among the threads of the ceremony. As a part of the research process, I offered tobacco with food to close the research in a good way. I consider co-creating the knowledge from this research process to be a way of celebrating this ceremony.

5.2 Implication of this research

This research has produced multiple methodological implications that may inform future research endeavours. Firstly, the utilization of the Indigenous Wholistic Framework to map out the evidence of Indigenous approaches and methods in adapting and developing health assessment tools has provided a guideline to conduct potential reviews pertinent to Indigenous health in the future. While the concept of 4Rs has been used in Indigenous health research, it has not been employed as a framework in any scoping review, to my knowledge. Given the rigorous nature of adapting and developing health assessment tools and creating them in culturally relevant and appropriate ways in Indigenous contexts, the process requires intensive investment of time and resources. The scoping review has provided evidence on a range of ethical approaches used by Indigenous and non-Indigenous researchers while adapting and developing health assessment tools. Also, this review has showcased the evolution of Indigenous health assessment research over time. A shift from conventional methods like literature reviews and expert opinions to more community-centred approaches such as yarning, photovoice, and consultation with community advisory groups, Elders, and other ways of involving communities in research processes. Furthermore, the current

research trends in Indigenous health assessment research reflect a movement toward strength-based approaches, thereby contributing to the decolonization of Indigenous research practices. Additionally, researchers have challenged Western concepts of health and promoted holistic approaches in defining health and wellbeing while adapting and developing the tools.

The second part of the thesis demonstrated how a non-Indigenous researcher can appropriately engage and collaborate with Indigenous community partners to build trust and work to bridge cultural and knowledge gaps. Although it was a challenge for the Indigenous health organization with limited capacity to partner with non-Indigenous health researchers, the project served as a mutual learning opportunity. Throughout the research process, we adhered to the principles of respect, responsibility and reciprocity. During the research process, my community partner and I were aware of our cultural differences and respected each other's differences. It was an opportunity to learn from each other's strengths that helped to overcome each other's weaknesses.

The focus groups conducted in the second phase provided insights into the challenges faced by health professionals in delivering dementia-related assessments and services. One significant issue highlighted by the participants was the absence of standardized and validated functional assessment tools specific for Indigenous population. This resulted in inconsistency among the health professionals in assessing dementia within Indigenous communities. The non-Indigenous health professionals expressed the lack of cultural understanding related to dementia and emphasized the need for training in Indigenous cultural practices. Moreover, participants discussed the importance of gathering collateral

information from family members, caregivers, or PSWs when family is not available. They even suggested conducting separate sessions with these informants, affirming the necessity for informant-based functional assessment tools. These are some of the potential areas for future research. The development of the culturally appropriate and relevant Indigenous Functional Assessment tool will help in addressing these issues to some extent.

Furthermore, they provided insights into the potential approaches and domains that need to be considered in developing a relevant and appropriate informant-based functional assessment tool in First Nations communities. These findings are significant as health professionals play a crucial role in assessing patients presenting with cognitive complaints. The input from the health professionals, along with the voices of the caregivers, is essential for developing tools that meet the needs of all stakeholders. Notably, the focus groups highlighted the challenges arising from fragmented health information systems, underscoring the importance of addressing systemic issues in health care delivery. Raising such issues from the health professionals' perspectives is crucial as this helps inform plans, strategies, and policies related to health care delivery.

5.3 Strengths and Limitations

One of the major strengths of this research was emphasizing the creation of relationships with partner organizations and CAG. This relationship was based on mutual respect for both me, a non-Indigenous researcher and Maamwesying, an Indigenous community-health organization. Throughout the research, the principles of 4R were always at the forefront of decision-making and adhered to the Tri-Council Policy on Ethical Conduct

for Research Involving Humans, and the local regulations and protocols of Maamwesying North Shore Community Health Services.

During the entire research process, I was aware of my cultural background and the potential biases that could arise due to my cultural perspectives. Whenever confusion occurred through cultural differences, I sought guidance from my supervisor and my community partner. However, this research was supervised by a team of Indigenous and non-Indigenous scholars who have years of experience working in the area of Indigenous health research, health policy research and qualitative research methods.

As a non-Indigenous person, I had an immense experience of cross-cultural learning and reflection. Importantly, the research needs were identified by the Indigenous communities who were partners to Maamwesying, rather than by the researcher. Maamwesying had been working over the years to provide quality dementia-related health services to communities. During the continuous engagement and discussion, Maamwesying felt this work fit within the broader work of developing a Memory Clinic and agreed to partner with me. There was mutual understanding and respect from both sides. Engagement with the CAG, and research team of Maamwesying and Noojmowin Teg Health Centre in all the stages of the research process, was crucial to this research. With Maamwesying, open communications have taken place regarding the academic and non-academic publications and presentations related to the research. The collaboration between Maamwesying and I, as well as the outcome of the results, were shared on national and international networks and platforms through presentations and publications.

One of the methodological limitations of the scoping review is that the full text screening and data extraction stages were conducted by a single reviewer. Initially, both the research assistant of my supervisor and I were involved in screening titles and abstracts. However, the assistant discontinued her work with my supervisor, and I was solely responsible for screening the full texts and extracting data. Although I sought feedback from my Supervisory Committee at every step of the scoping review, there remains the possibility of individual biases and potential errors during data extraction and mapping out the approaches and methods of tool adaptation and development process. Another limitation of the review is the lack of engagement with the communities in the data analysis phase of the scoping review, which was intended earlier. Instead, I presented the results to the community partner and members of CAG.

Given the limited number of Indigenous health professionals providing dementia-related services to First Nations communities, non-Indigenous health professionals serving in these communities were included. Although the aim was to include only health-professionals in the focus groups, other community members and administrative staff participated in the focus group. Thus, out of 17 participants, only ten contributed to the discussion. During the discussions, I tried to include the voices of each participant, but the discussion was largely dominated by health professionals who directly provided dementia-related assessment and services.

Finally, I acknowledge and recognize the limitations of my position as a non-Indigenous researcher writing about this topic, despite the fact that I came to learn and respect researching within the frame of the Indigenous Research Paradigm. This was a

preliminary process of laying a foundation for Maamwesying to develop the Indigenous Functional Assessment tool, and the foundation has been established in a good way.

5.4 Directions for Future Research

This preliminary study aimed to lay the foundation for my partner organization, Maamwesying, to develop an informant-based Indigenous functional assessment for dementia in the communities that they serve. Maamwesying has been providing health services and dementia assessment through a community-based memory clinic in Anishinaabe communities along the north shore of Lake Huron, in collaboration with the Sault Ste Marie Family Health Team and Alzheimer's Society. The *CICA* is being used to assess the cognitive aspect of people with dementia. However, there is no existing functional assessment tool that is culturally appropriate and relevant to Indigenous communities for comprehensive dementia assessment.

The study's findings suggested that we further need to understand the construct of function from Indigenous caregiver's perspectives. In addition, as a researcher, we need to reflect whether an informant based functional assessment tool that is standardized is the right next step or how to balance the tension between the standardization process and relational approach in tool development. Maamwesying has obtained some funding for the tool's further development. However, the formation of a new tool is an extensive process. Once we have a tool, it must go through the piloting, reliability, and validity process. It should have the highest degree of sensitivity and specificity to identify actual dementia cases.

Indigenous research evolves with time. This research went through an iterative process to reach the existing stage. Similarly, the next step is supposed to have interviews with family or caregivers to understand their perspectives on how they want the tool and how some Indigenous activities of daily living are different from the daily activities of the general population. However, for the next step, there will be consultation with the CAG, the Senior PAC, and other experts on tool development. I presented the research approach and findings with my community partner at the International Indigenous Dementia Research Network 1st Annual Conference, where researchers from Australia, Aotearoa/New Zealand, the United States and Canada were present. Some of them were among the ones who had developed the original KICA and other assessment tools specifically for Indigenous populations. However, none of them has developed culturally appropriate and relevant functional assessment tools that specifically focus on IADLs. Those researchers were keen on partnering with us to develop this tool. There is potential for partnering with international researchers to develop this tool.

This research has opened up the discussion for laying the foundation for the development of functional assessment tools in a culturally safe and relevant way. Standardized tools have been modified and adapted in the Indigenous context without understanding the history of colonization, resulting in health inequities and the harm faced by Indigenous people in Canada. Following the principle of the 4Rs and the Indigenous research paradigm, as a researcher, I tried to deconstruct my beliefs and perspectives to understand better and utilize the Indigenous ways of knowing and doing in this work. However, it was challenging to challenge the existing course of tool development that focuses on

psychometric properties, with the positive intention and the combined effort of Maamwesying, my Supervisory Committee, CAG, SPAC and the participants towards decolonization. As a researcher, I acknowledge the need to navigate the tension between developing standardized assessment tools with normative data and a more relational approach that is congruent with Indigenous ways of knowing, being and doing. This process requires significant time, resources, and engagement with the community members to whom this tool will be developed.

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Appendices

APPENDIX A Research Ethics Board Approval



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

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

TYPE OF APPROVAL / New /	Modifications to project X /	Time extension X
Name of Principal Investigator and school/department	Nabina Sharma, School of Kinesiology and Health Sciences, supervisor: Jennifer Walker, committee: Elizabeth Wenghofer, Taima Moeke-Pickering, Jeannette Lindenbach	
Title of Project	Development of an Indigenous Functional Assessment tool	
REB file number	6021023	
Date of original approval of project	June 28, 2021	
Date of approval of project modifications or extension (if applicable)	November 29, 2022	
Final/Interim report due on: (You may request an extension)	June 28, 2023	
Conditions placed on project		

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

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

Congratulations and best wishes in conducting your research.

A handwritten signature in blue ink, appearing to read "SHoy".

Sandra Hoy, PHD, Chair, Laurentian University Research Ethics Board

APPENDIX B Terms of Reference for Community Advisory Group

The community advisory group's key role is to ensure that the team and the project are grounded in First Nations perspectives throughout the research process. I am looking for new members for CAG.

Members of the community advisory group will be expected to:

- Participate in the meeting to discuss the project and provide feedback on the planning of the research process as the project evolves.
- Provide support in identifying potential care partners for in-depth interviews and health professionals for the focus group.
- Provide feedback on the scoping review that the research is working as the first paper of the Ph.D. requirement.
- Assist in analyzing the qualitative data obtained from focus groups and in-depth interviews.
- Collaborate on disseminating the tool with various stakeholders like media personnel and policymakers.

Members of the community advisory group will be respected and acknowledged as key contributors to the research team. They will be offered an honorarium for their participation in the meeting.

APPENDIX C Research Information

Listening to the loved ones: Study on informing the development of functional assessment tool

Dementia is a syndrome characterized by a progressive decline in cognition that eventually interferes with an individual's usual functioning. Dementia affects all areas of cognition, such as memory, organization, perception, abstraction, judgement, language, reasoning, and attention. In Canada, dementia is rising substantially among the Indigenous population. The burden of multiple chronic conditions among Indigenous people and other health and social issues has overshadowed the increasing burden of dementia resulting in the late diagnosis.

The decline in the cognitive functions of an individual affects their everyday activities of daily living. Everyday activities of daily living are categorized as basic activities of daily living (BADL) and instrumental activities of daily living (IADL). BADL consists of self-care such as eating, dressing, using toilets and instrumental activities of daily living (IADL) such as cooking, taking medications, housekeeping, using a phone, handling finances, and shopping occurs in dementia. As IADLs decline in the initial stage with cognitive decline, whereas BADLs are the ones to decline in the later stage, IADLs are considered an early indication of dementia.

Various assessment tools exist to assess the cognitive and functional decline in older adults; however, most of the widely used assessment tools are developed and focus primarily on Western populations. The tools developed and validated for the Western English-speaking population may not apply to diverse people and cultures. Thus, the Canadian Indigenous Cognitive Assessment (CICA) tool has been developed and validated to address the need for a culturally safe and grounded cognitive assessment tool for Indigenous people. While validating the instrument, the physicians and the community involved identified the need to have an informant-based functional assessment tool that assesses the activities of daily living of loved ones.

Developing a tool for a specific population is rigorous work, and the concept and domains to create a tool need to be understood first. Most of the available tools are "expert-driven," having been designed by clinicians and researchers and have adequately failed to consult and incorporate the perception of the populations to which they are intended to apply. Thus, we aim to conduct community-engaged research to identify the concept and domains necessary for developing a functional assessment tool. This research will be a grounding work that will inform the tool's development.

We have partnered with the Maamwesying North Shore Community Health Services and formed a Community Advisory Group (CAG). The CAG will be responsible for informing the research process, providing feedback in planning, recruiting participants, analyzing the collected qualitative data and providing recommendations for developing tools. Currently, we have Elder Jean Andrews from Birch Island, Mariette Sutherland, and Jessica Bertuzzi from Alzheimer's Society of Sudbury on our CAG, and we are looking for two more members for CAG.

We will conduct a focus group with the health professionals working with Indigenous people's cognitive health assessment and in-depth interviews with the care partners. The qualitative data obtained from the focus group and in-depth interviews will be analyzed with CAG and develop recommendations necessary for creating the functional assessment of the Indigenous older adults.

APPENDIX E Focus Group Guide

Preliminary Study on Developing an Indigenous Functional Assessment Tool

- You have provided health services to Indigenous older adults for quite a significant time. What are your experiences working with the communities?
- What cognitive and functional assessment tools have you been using in communities?
- What challenges do you face while using those assessment tools?
- What are the areas that existing functional assessment tools are not able to cover in First Nations population?
- What are the primary areas of function that prompt First Nations clients to present with cognitive complaints?
- While working in cognitive and functional assessment of older adults, what important aspects of functions that should be included in a functional assessment tool that is specific to First Nations?
- What approaches of functional assessment are important to ensuring that the individual and caregivers feel comfortable?
- What do you want to hear from the family members/caregivers about the functional decline?
- What should we be asking to the family members/caregivers in the functional assessment tool?
- What cultural practices do older adults perform as Instrumental Activities of Daily Living (IADL), and how can it be assessed for early diagnosis of dementia?
- What do you think, how the family members want their loved ones to be assessed?
- Is there anything else that you would like to add?

Additional questions

- Who do you think is the best person to administer the tool for assessing IADL?
- What should be the format of the tool?

APPENDIX F Information and Consent Form



Information Letter

Study: Preliminary study on developing an informant-based Indigenous Functional Assessment tool in First Nations communities.

Principal Investigator:

Nabina Sharma, Ph.D. Candidate, Interdisciplinary Rural and Northern Health Program, Laurentian University, 935 Ramsey Lake Road, Sudbury, Ontario, P3E2C6; nsharma2@laurentian.ca

Thesis Supervisor:

Jennifer Walker, Ph.D., Associate Professor, Department of Health Research Methods, Evidence & Impact, McMaster University, jennifer.walker@mcmaster.ca

Committee Members:

Elizabeth Wenghofer, Ph.D., Full Professor, School of Kinesiology and Health Sciences, Laurentian University, EWenghofer@laurentian.ca

Taima Moeke-Pickering, Ph.D., Full Professor, School of Indigenous Relations, Laurentian University, tmoekepickering@laurentian.ca

Jeannette Lindenbach, Ph.D., Associate Professor, School of Nursing and Allied Health Professions, Laurentian University, jm_lindenbach@laurentian.ca

Community Partner: Maamwesying North Shore Community Health Services Inc.

Invitation to participate: I, Nabina Sharma, invite you to be a part of our study.

This study is conducted in partnership with Maamwesying North Shore Community Health Services Inc.

Nature and goal of the study: Existing functional assessments may not assess functional status of First Nations clients in a relevant, culturally appropriate, and safe manner. We want to bring together health professionals' knowledge, experiences, and perspectives to explore the domains for developing a culturally relevant and appropriate informant-based functional assessment tool. This will allow us to create a tool that will contribute to a comprehensive assessment of dementia in First Nations communities.

Participation: If you agree to be in this study, we will ask you to:

- Fill out a questionnaire or answer questions about yourself (ex. Age, role, etc)
- Participating involves attending a 90-minute focus group to explore:
 - the important aspects of function that should be included in a functional assessment tool that is specific to First Nations.
 - the primary areas of function that prompt First Nations clients to present with cognitive complaints.

- approaches to functional assessment that are important to ensuring that the individual and caregivers feel comfortable.

Risks: There is no legal or financial risk in coming to the events. There is a minimal risk that emotional distress may be created when discussing the difficulties experienced by Indigenous people living with dementia. If you experience distress or discomfort during the focus group, you can terminate your participation without providing a reason.

Benefits: This research will lay foundation for developing the informant- based functional assessment tool that is culturally relevant and appropriate to the First Nations communities. The development of this tool will contribute to comprehensive assessment of dementia in First Nations communities.

Confidentiality and anonymity: A code will be added to your forms. Only the principal investigator and the supervisor will have access to your data. All team members have signed a confidentiality agreement saying that they will not share anything they see or hear during the study. A member of the research ethics board may review the data to verify that the study is well managed. Confidentiality cannot be assured if participants speak outside the events.

Storage of data: We will scan your forms and shred their paper versions with a secure disposal system. We will store all digital data in a specific file with encryption. We will protect this file with a password on the principal researcher's Google Drive. We will also protect this Google Drive with a password. We will also store all data in Maamwesying North Shore Community Health Services archives. Maamwesying North Shore Community Health Services will control passwords and access. We will keep the data for ten years after the publication of the study. Then, we will remove and digitally shred the digital data from Google Drive.

Publication: Nabina Sharma will publish all work related to this study in collaboration with Maamwesying North Shore Community Health Services.

Right to withdraw from study: Your participation in this research is voluntary. It is your choice whether to participate or not. If you feel uncomfortable about any discussion, you can refuse to provide your opinion or withdraw from the focus group at any time without providing a reason. You will still receive \$75 as an honorarium for your participation.

Acceptance: If you agree to be in the study, fill out the consent section on the next pages. For more information about this study, contact Nabina Sharma by email at nsharma2@laurentian.ca or call me at 416278-8533. Alternatively, you can contact my supervisor, Dr. Jennifer Walker at jennifer.walker@mcmaster.ca or Edith Mercieca at edith.mercieca@nmjinoeyaa.ca, Director of Home and Community Support Services, Maamwesying North Shore Community Health Services Inc. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact Research Ethics Officer, Laurentian University Research Office Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030 Email: ethics@laurentian.ca.

Email _____

Consent Form

I have read the information and consent form. I agree to be in the study "Preliminary study on developing an informant-based Indigenous Functional Assessment tool in First Nations communities" led by Nabina Sharma, Ph.D. Candidate.

Yes
 No

May we record the event? This is how we will use it:

- Nabina Sharma will copy it out. No personal names will be used. We will delete the recordings at the end of the project.
- Information from both events will be:
 - Categorized
 - Used to create a domain and ideas for functional assessment tool.
 - Shared with you in writing or in person.
 - Information will be used to write an article about the study and prepare a dissertation to fulfill the requirement of a degree of Doctor of Philosophy (Ph.D.).

If any person says no to both audio and video, we will not record the events. Instead, we will use notes taken by the researchers for the analyses.

I allow AUDIO/VIDEO recording of the event.
 I allow AUDIO recording of the event.
 I do not allow AUDIO or VIDEO recording.

Additional consents

May we talk to you after the event about using something you said in the article?

After the event, we will show you the quote, it's context and how it will be used. After you see it, we will ask for your consent to use it.

Yes
 No

Do you want to be invited to a review where we talk about the results of the study?

Yes
 No

Signature _____

Date _____

APPENDIX G Confidentiality Agreement

12/27/23, 4:14 PM

Confidentiality Agreement

Confidentiality Agreement

During my participation in the research project "Preliminary study on developing the Indigenous Functional Assessment tool in First Nation communities", I acknowledge that I will be given access to participant information that is deemed sensitive and/or confidential.

* Indicates required question

1. Email *

2. I agree that: *

- A. I shall not share this information, material or documents (information) with persons who are not authorized to have this information.
- B. I shall not communicate or publish such information without the consent of the Maamwesying North Shore Community Health Services Inc.
- C. Should I receive any such information, I will accept full responsibility to ensure the confidentiality and safe-keeping of this information.
- D. I shall take every reasonable step to prevent unauthorized parties from examining and/or copying any such information.

Mark only one oval.

Yes

No

continued

This document represents my commitment to treat any information which is entrusted to me during the research project in a manner that respects the privacy of participants, healthcare providers and involved organizations, including information that does not identify individual healthcare providers, institutions or participants.

<https://docs.google.com/forms/d/1D0C3e5mddMSDqYFIATzhKzKxWvyVjpbGwSleAcLM/edit>

1/3

3. I agree to respect the following rules regarding the treatment of information with which the organization is entrusted: *

A. I will not allow another person to use my authorized access (e.g. username and password) to gain access to information regarding the project.

B. I will only access, process and transmit information using authorized hardware, software and other equipment.

Mark only one oval.

Yes

No

4. I have read this confidentiality agreement and understand that the conditions as described in this agreement will remain in force even if I cease to have an association with the project.

Please write your name below as a representation of your digital signature and consent.

This content is neither created nor endorsed by Google.

Google Forms

APPENDIX H Methods for Adapting or Developing Tools

Table 5 Methods for Adapting or Developing Tool

Author	Year	Target group	Indigenous Population	Country	Measure	Adaptation/ Development	Methodology
(Gupchup, 2001)	2001	Adult	Native American	USA	Health Related-Quality of Life	Adaptation	Focus group with the participants
(Palmer, 2004)	2004	Adult	Māori	New Zealand	Well-being	Development	Literature review and discussion with academicians and community people on concepts
(Vindigni, 2004)	2004	Adult	Aboriginal and Torres Strait Islander (rural)	Australia	Musculo-skeletal	Development	Literature review and key informant discussions
(LoGiudice et al., 2006; Smith, 2007)	2006	Older adult	Aboriginal and Torres Strait Islander	Australia	Cognition	Development	Consultations with diverse Indigenous Councils and communities, Indigenous and non-Indigenous health professionals, clinicians, interpreters; Literature review
(Schlesinger et al., 2007)	2007	Adult	Aboriginal and Torres Strait Islander	Australia	Alcohol, drug and mental health risk	Development	Focus Group with multiple groups ranging from academic experts (to test the already selected item), health workers (content and administration feasibility) and Indigenous people from communities

							(acceptability and comprehension of the new tool)
(Campbell et al., 2008; Hayes, 2010)	2008	Adult Women	Aboriginal and Torres Strait Islander	Australia	Postnatal Depression	Adaptation (translated)	Indigenous Reference Group, focus group, iterative consultation with Indigenous health worker, community elders and groups
(Thomas et al., 2010)	2010	Youth	Aboriginal and Torres Strait Islander	Australia	Social and emotional well-being	Development	Literature review and iterative consultation with community members and mental health professionals at all stages of tool development
(Haswell et al., 2010)	2010	Adult	Aboriginal and Torres Strait Islander	Australia	Mental health	Development	Qualitative interviews with Indigenous people to develop themes, refined and piloted content through workshops with mental health researcher and consultative workshop with Indigenous participants for further input and develop tree as a metaphor
(Amberber, 2011)	2011	Adult	Māori	New Zealand	Aphasia	Adaptation	Discussions with bilingual community consultants on objective, language material and tool to be adapted; followed standard adaptation process by the consultants
(Brown et al., 2013)	2013	Adult men	Aboriginal and Torres Strait Islander	Australia	Depression	Adaptation	Qualitative study for concept identification, literature review on existing instruments, focus group with Elders and bilingual translators, followed standard translation procedure and final focus group for difficult items

(Fitzpatrick et al., 2013)	2013	Adult	Aboriginal and Torres Strait Islander	Australia	Fetal alcohol spectrum disorder	Development	Literature review, questionnaire developed by experts and refinement in consultation with Indigenous community members
(Young et al., 2013, 2015)	2013	Children	First Nation (Odawa, Ojibway and Pottawatomi)	Canada	Health and well-being	Development	Multistage process- Literature review, Advisory Group formation, focus groups to explore concepts, open community consultation, Photovoice with children, consultations with advisory group, experts, academicians, participants and community people and finalization of the tool
(Dionne, 2014)	2014	Children	First Nation (Mohawk population)	Canada	child development across multiple domains	Adaptation	Questions modified, visuals changes according to cultural norms and modified according to participants feedback-not much description on process
(Almeida et al., 2014)	2014	Adult	Aboriginal and Torres Strait Islander	Australia	Depressive Symptoms	Development	Items generated through literature review and wording revised for linguistic and cultural relevance by research team and community assistant
(Stewart & Gardner, 2015)	2015	Adult	Māori	New Zealand	Occupational stress and well-being	Development	Consultation with Māori health worker for need identification, item generated from Western and Māori focused literature, consultations with health practitioners, based on Māori Outcome Dimension framework tool developed through iterative consultation

(Janca et al., 2015)	2015	Adult	Aboriginal and Torres Strait Islander	Australia	Social and emotional well-being	Development	creation of Indigenous mental health gallery through community consultations, yarning process to listen to the stories and information from key informants such as health workers, social workers and psychologists to develop the initial draft of HANAA instrument and written and oral feedback from the key informants.
(Smith, 2016)	2016	Older adult	Aboriginal and Torres Strait Islander	Australia	Function	Development	Consultation with range of specialist and Indigenous community members and literature review of existing tools
(D'Aprano et al., 2016)	2016	Children	Aboriginal and Torres Strait Islander	Australia	child development across multiple domains	Adaptation	Interviews with Indigenous and non-Indigenous health workers, specialist and community experts on the need of adaptation of the tool; consultations with Indigenous health services and community member to reach agreement for the purpose of the project; consultation with linguists, childhood experts, authors who developed original tool and developed culturally appropriate figures and illustrations by local artists to translate tool in Indigenous context and final consensus with the committee members.
(Brown, 2016)	2016	Adult men	Aboriginal and Torres Strait Islander	Australia	Psychosocial stress and depression	Development	Questionnaire domain as a working model developed through key-informant interviews, literature reviews and focus groups and refined in consultations with key informants; consulted key informant for additional items and focus group for reviewing questionnaire

(Barraza & Bartgis, 2016)	2016	Youth	Native	USA	Personal Balance	Adaptation	Formation of Youth Council and capacity building of the Youth Council member; existing tool taken to youth council; open discussion within the Youth Council and Youth Council adapted the item of the tool that is relevant and meaningful for youth
(Kotz et al., 2016; Marley et al., 2017)	2016	Adult Women	Aboriginal and Torres Strait Islander	Australia	Antenatal and Perinatal Depression	Development	Literature review to identify the problem; formed community advisory group; focus group using yarning approach to work on wording and formatting of the translated version of EPDS tool in Indigenous context, iterative consultation with the advisory group, health professionals, language and cultural groups and community members to develop the first part of the tool and second part was developed to explore the comprehensive understanding of women in relation to depression through yarning approach
(Butten, 2021, 2021)	2019	Children	Aboriginal and Torres Strait Islander	Australia	Health Related-Quality of Life	Development	Yarning approach and interviews used to identify the concept of quality of life in children experiencing chronic illness from parents and caregivers' perspectives; yarning used to develop the items; Indigenous academicians, health workers and clinicians working with Indigenous children ranked those items and iteratively reviewed to reach to consensus; consultations with Indigenous community members for the appropriateness, acceptability, usability and applicability of the tool

(Peters & Peterson, 2019)	2019	Adult	Dakota Wicohan community	USA	Health and well-being	Development	Partners and research team used Indigenous epistemologies and Community Based Participatory Action Research to inform their work, research partners included several staff, elder advisors, and board members from community, research partners shaped all phases of the research projects (e.g. conceptualization, design, data collection, data analysis and writing)
(Jacklin et al., 2020)	2020	Older adult	First Nation (Anishinaabemowin)	Canada	cognition	Adaptation	An iterative cycle of monthly consultations between an 11-member expert Anishinaabe language group and the investigators, with ad hoc consultations with an Indigenous Elder, a community advisory council, and the original tool (KICA) authors helped in adapting the tool.
(Ching, Saetre-Turner, et al., 2020)	2016	Children	Aboriginal and Torres Strait Islander	Australia	communication or speech and language problems based on parent report	Development	Literature review and consultation with experts to refine the scope of the tool and important components of tool; co-design workshop with Indigenous community members to generate the relevant items and refined and re-worded in response to feedback through an iterative process
(Ching, Hou, et al., 2020)	2020	Children	Aboriginal and Torres Strait Islander	Australia	Parents' report on children's hearing and listening problem	Development	co-design workshop with health workers in urban, rural, and remote Indigenous communities participated and were refined in a culturally appropriate context. Pictures were designed and refined through feedback from workers and families, culturally appropriate representation of the respective items were finalized.

(Jones et al., 2020)	2020	Children	Aboriginal and Torres Strait Islander	Australia	Early communication development	Development	Qualitative interviews with Indigenous mothers and generated the items. Data analyzed in consultation with Indigenous community members, parents/caregivers, and non-Indigenous linguist experts and additional items were included through discussion.
(Gomez Cardona et al., 2021, 2021)	2021	Adult	First Nation (Mohwak/Kanien'kehá:ka people of Quebec)	Canada	mental health	Adaptation	Advisory committee formed. Researchers presented an existing mental health assessment tool to the advisory committee; advisory committee selected Growth Empowerment Measure to be adapted in Kanien'kehá:ka context. 12 advisory group members identified. 5 focus groups and one individual interview- informal discussions with the co-researcher and a Faith Keeper to get further cultural insight. Qualitative, collaborative, participatory action, methodology consistent with Indigenous perspectives of understanding and knowledge transfer to contribute to decolonizing approach
(Smith, 2021)	2021	Older Adult	Aboriginal and Torres Strait Islander	Australia	Health Related- Quality of Life	Development	An Elder governance group formed which helped in planning, developing and informing research question, project name, interview question, themes, and framework and adaptation of the tool. Service provider advisory group provided information on tool preference to facilitate the tool being translated into practice. Yarning circles conducted; semi-structured interviews on Quality of Life; thematic analysis conducted by the Indigenous and non-Indigenous

							researchers, and key themes discussed, reflected and refined with Elder governance group and triangulation of data with service provider advisory group. Enabling in-depth participatory involvement of Elders in all stages of the research process ensured that the process was culturally safe and informed by Aboriginal worldviews, ways of knowing, being, and doing.
(Benn, 2021)	2021	Older adult	Aboriginal and Torres Strait Islander	Australia	Obstructive Sleep Apnoea	Development	Focus group consisting of Indigenous representative, anthropologists, clinicians and researchers reviewed existing materials, suggested alternative questions on existing tool, additional culturally relevant pictorial representation and simple language. Based on the suggestions, the group developed the tool over several meetings and reached the final approved version.

APPENDIX I Search Strategy for across various database and grey literatures

Table 6 Search Strategy across Database

Database	Syntax	Articles Retrieved
PubMed	<p>(((((((("Indigenous Peoples"[Mesh] OR "Alaskan Natives"[Mesh]) OR "Indigenous Canadians"[Mesh]) OR "Indians, North American"[Mesh]) OR "Oceanic Ancestry Group"[Mesh]) OR ((Indigen*[Title/Abstract] OR Aborig*[Title/Abstract] OR "Torres Strait Islander*"[Title/Abstract] OR Indigenous[Title/Abstract] OR Aboriginal[Title/Abstract] OR "Native Hawaiian"[Title/Abstract] OR "First Nations"[Title/Abstract] OR Metis*[Title/Abstract] OR Inuit*[Title/Abstract] OR Maori*[Title/Abstract] OR "Australian Aboriginal"[Title/Abstract]) OR ("Native American"[Title/Abstract]))) AND (tool*[Title/Abstract] OR instrument*[Title/Abstract] OR test*[Title/Abstract] OR scale*[Title/Abstract] OR question*[Title/Abstract])) AND (assess*[Title/Abstract] OR screen*[Title/Abstract] OR diagnos*[Title/Abstract] OR measur*[Title/Abstract])) AND (adapt*[Title/Abstract] OR develop*[Title/Abstract] OR construct*[Title/Abstract])) NOT ("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review") Filters: Free full text, Full text, Journal Article, Humans, English, from 2000 - 2021</p>	789

<p>APA Psych Info</p>	<p>(((((ab("Indigenous Canadians" OR "Indigenous Peoples" OR "Indians, North American" OR "American Natives" OR "Oceanic Ancestry Group" OR Indigen* OR Aborig* OR Torres Strait Islander* OR Indigenous OR Aboriginal OR "Indian, North American" OR "Alaskan Native*" OR "Native Hawaiian*" OR "First Nation*" OR Metis* OR Inuit* OR Maori* OR "Australian Aboriginal") AND ab(assess* OR screen* OR diagnos* OR measur*) AND ab(adapt* OR develop* OR construct*) AND ab(tool* OR instrument* OR test* OR scale* OR question*) NOT ("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review"))) AND rtype.exact("Peer Reviewed Journal" OR "Journal Article")) AND la.exact("English") AND pd(20000101-20211031)) AND rtype.exact("Peer Reviewed Journal" OR "Journal Article")) AND la.exact("English")) AND rtype.exact("Peer Reviewed Journal" OR "Journal Article")) AND la.exact("English")) AND PEER(yes) AND pd(20000101-20211031)</p>	<p>554</p>
<p>CINAHL</p>	<p>AB ((MH "Indigenous Peoples+") OR (MH "Aboriginal Canadians+") OR (MM "Aboriginal Australians") OR (MM "First Nations of Australia") OR (MH "Native Americans") OR (MH "Alaska Natives") OR "Indigenous People" OR "oceanic ancestry people" OR (MH "Torres Strait Islanders") OR (MH "Maori") OR "Native Hawaiian" OR "First Nation*" OR Metis* OR Inuit* OR "Indigenous Canadians" OR "Indians, North American") AND AB (assess* OR screen* OR diagnos* OR measur*) AND AB (tool* OR instrument* OR test* OR scale* OR question*) AND AB (adapt* OR develop* OR construct*) NOT TX ("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review")</p>	<p>123</p>

-	AB ((MH "Indigenous Peoples+") OR (MH "Aboriginal Canadians+") OR (MM "Aboriginal Australians") OR (MM "First Nations of Australia") OR (MH "Native Americans") OR (MH "Alaska Natives") OR "Indigenous People" OR "oceanic ancestry people" OR (MH "Torres Strait Islanders") OR (MH "Maori") OR "Native Hawaiian" OR "First Nation" OR Meris* OR Inuit* OR "Indigenous Canadians" OR "Indians, North American") AND AB (assess* OR screen* OR diagnos* OR measur*) AND AB (adapt* OR develop* OR construct*) AND AB (tool* OR instrument* OR test* OR scale* OR question*) NOT TX ("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review")	51
Web of science core collection	((AB=((Indigen* OR Aborigin* OR "Native American" OR "Indian, North American" OR "Torres Strait Islander" OR Maori* OR "Indigenous Canadians" OR "Alaskan Native*" OR "Native Hawaiian*" OR "first nation*" OR metis* OR Inuit* OR "Australian Aboriginal"))) AND AB=(assess* OR screen* OR tool* OR test* OR instrument* OR measure* OR question*)) AND AB=(develop* OR adapt* OR construct*) NOT ALL=(("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review"))	374
Medline	((((AB=(Indigen* OR Aborigin* OR "Native American" OR "Indian, North American" OR "Torres Strait Islander" OR Maori* OR "Indigenous Canadians" OR "Alaskan Native*" OR "Native Hawaiian*" OR "first nation*" OR metis* OR Inuit* OR "Australian Aboriginal"))) AND AB=((assess* OR screen* OR tool* OR test* OR instrument* OR measure* OR question*)) AND AB=((develop* OR adapt* OR construct*))) NOT AB=(("review of literature" OR "literature review" OR "meta-analysis" OR "systematic review" OR "comprehensive review" OR "critical review"))	383
Australian Indigenous Health info data set	(assessment tool) or (screening tool) or (diagnostic tool) or (instrument) or (questionnaire) or (scale) or (test) in (title or abstract)	124

<p>Indigenous Health Portal (University of Saskatchewan)</p>	<p>(develop* OR construct* OR adapt*) AND (assess* OR screen* OR diagnos* OR measure*) AND (tool* OR instrument* OR test* OR scale* OR question*) Articles > Scholarly peer reviewed</p>	<p>28</p>
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