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Advancing Indigenous-Centred Dementia Care: A Qualitative Study

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Advancing Indigenous-Centred Dementia Care: A Qualitative Study

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ABSTRACT

Indigenous populations in Canada are experiencing increased rates of dementia compared to non-Indigenous populations, yet there remains a lack of culturally safe, Indigenous-centred dementia care. The current dementia care system is ineffective and does not address the care and treatment needs of Indigenous people living with dementia and their care partners. The aims of this project were to gain an understanding of the experiences of dementia for Indigenous people living with dementia, their care partners, families, and communities and to determine the foundational principles of culturally safe approaches to Indigenous-centred dementia care. This work is framed within an Indigenous worldview and informed by Indigenous paradigms of relationality. This research used a Métis methodological approach, Keeoukaywin (The Visiting Way) and qualitative semi-structured interviews to collect in-depth data with 12 participants throughout Alberta. Participants included Indigenous people living with dementia, care partners, and community members and used thematic analysis to create a framework to improve culturally safe dementia care. The framework includes three domains that inform Indigenous-centred dementia care including relationality, being well, and safety. Each of these three domains include subdomains including social, cultural, and physical characteristics informed by participant experiences. This framework provides a foundation that can be integrated into the creation of an Indigenous-centred dementia care approach.

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DEDICATION

This thesis is dedicated to every person who shared their stories with me, I appreciate you all.

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LIST OF DEFINITIONS

Alzheimer's Disease: a type of dementia that causes chronic, irreversible neurodegenerative disease that impacts brain cells, resulting in cognitive deterioration over time.

Anti-amyloid drugs: drugs that target and reduce the abnormal accumulation of amyloid beta plaques in the brain.

Anti-tau drugs: drugs that target and reduce the abnormal accumulation of tau proteins in the brain.

B-secretase inhibitors: drugs that block the activity of the enzyme beta-secretase.

Cholinesterase inhibitors: drugs that prevent the breakdown of the neurotransmitter acetylcholine by inhibiting the enzyme cholinesterase.

Cisgender: a person whose gender identity matches the sex they were assigned at birth.

Colonialism: a process through which a foreign people establish control over a territory leading to the political, economic, and cultural subjugation of the colonized region and its people.

Dementia: a set of symptoms that includes memory loss, changes in mood, difficulties with thinking, language, or problem solving, and that impact daily life.

HIV: Human Immunodeficiency Disease.

Indigenous: referring to the original inhabitants of a specific region or country that have distinct cultural, social and historical relationships to the lands they live or lived on that predate colonial contact. In a Canadian context this includes First Nations, Métis, and Inuit Peoples.

Monoclonal antibodies: laboratory-produced molecules designed to mimic the body's immune response to pathogens.

Reflexivity: an ongoing, fundamental process of reflecting on and critically examining one's own beliefs, values, experiences, and biases in relation to a particular subject or

social context. This involves sitting with the discomfort when recognizing one's privilege, and actively practicing self-awareness during the research process.

TRC: Truth and Reconciliation Commission of Canada. The TRC is a report published in 2015 with 94 Calls to Action for all areas of society.

UNDRIP: United Nations Declaration on the Rights of Indigenous Peoples that outlines international guidance on the rights to self-determination and sovereignty of global Indigenous Peoples.

1.0 INTRODUCTION AND BACKGROUND

1.1 Positionality and Journey

Before I begin, examining my subjectivity, biases, and values is critical to this research process (Green & Thorogood, 2018). Therefore, it is necessary to situate and position myself within my journey of becoming involved in Indigenous health equity research and the context of this research. I am a cisgender white woman descended from European settlers and therefore my interpretations of the data will be informed by my experiences and privileges. During this process I have attempted to be critically self-aware (Smith, 2021) by openly describing and discussing these experiences and being reflexive about the impact that they have had on the research. As a non-Indigenous researcher engaging in research with Indigenous communities, I recognize the immense privilege of being invited into these spaces and have endeavoured to take part in the research practice with gratitude and humility. I am aware of the harm caused by western ways of practicing harmful research on Indigenous people and I have tried to immerse myself in ethical ways of doing research with Indigenous peoples.

The journey of how I got to where I am in this research process is important as it has set the foundation for my appreciation for research. I started my career working in health settings as an administrative assistant in a diabetic foot and wound clinic at 17 years old. Through interaction with patients, I learned about person-first care, the importance of

empathy, how to treat people with dignity, as well as power dynamics between care providers and patients.

After this job, I went on to work in a mental health office where there were no patients to directly interact with. I sat at a computer and entered data about patient interactions with healthcare workers. The human experiences behind these statistics were demoted to data entry points. The days working this job were very difficult and I found that my empathy was hardening and I was becoming cavalier about mental health issues, including my own. After several years in this position, I began working at the Calgary HIV clinic. I often interacted with patients in the hallways during their administrative check-in, and it was impossible to view them simply as numbers or test results. My empathy was growing back after the severe over-pruning it received.

In late 2020 I started looking for supplemental jobs and felt pulled towards doing research on COVID-19. At that time, in-hospital clinical trials for COVID-19 treatments for people were commencing and this felt like something I could contribute towards to make a difference. At first, this position was enjoyable and fulfilling. I was on the COVID-19 units talking with people, seeing the human side of the pandemic instead of only seeing the daily updates about numbers of new cases. Something shifted the day I received a call on my cell phone from a son whose father had consented to the study and was randomized to standard-of-care treatment instead of the clinical treatment. The son begged me to change his father to the treatment arm of the study. As I ran my report for the next batch of

patients, I realized his father died a few days after we spoke. I felt like I was wielding power over these people who were scared, isolated, and desperate for a cure.

These stories are significant because every job and experience has coloured in pieces of relevance and consideration for me as a researcher, and more importantly, as a human. Although I feel reticence to take up so much space with these stories, they are fundamentally important in the ways I now engage with Indigenous research. Recognizing that where I am from and who I know has led to me receiving opportunities that may be out of reach for others is a lesson in how colonization operates and how I have benefitted from a system that has hurt others. I have learned first-hand about person-centred care, respect, relationality, trust, and the humanness behind numbers and this has made me value both Indigenous methodologies and qualitative research. I hope this project highlights the fact that researchers should respect the stories that people are willing to share and that research should be done *with* people, not *on* people.

1.2 Study Purpose

The conceptualization and understanding of dementia from Indigenous Peoples' perspectives can assist with addressing health inequities. Historically, dementia has not been described by Indigenous people as a pathologized disease, as it is often presented in western medicalized systems (Pace, 2020). In some Indigenous cultures memory loss or cognitive decline is attributed to a natural aging process. These non-pathologized

Indigenous constructions of dementia may lead to decreased care-seeking (Racine et al., 2021) and are important for consideration when trying to address dementia with Indigenous people. Accurate and timely diagnoses for dementia are well known to inform targeted treatments and interventions (Livingston et al., 2020), but distrust in medical systems due to racism and unsafe care has led to delays in both biomedical care and diagnoses, as well as effective treatment for some people living with dementia (Pace, 2020). Today, aging Indigenous populations and increased dementia incidence have uncovered the lack of evidence and knowledge possessed by western health systems about how to support Indigenous people living with dementia and their care partners and communities (Statistics Canada, 2022; Ward et al., 2018) in culturally safe and informed ways. In 2015, the Truth and Reconciliation Commission of Canada released 94 Calls to Action for all levels of government, organizations, and individuals to make societal changes to work toward reconciliation. The Truth and Reconciliation Commission of Canada Call to Action #22 specifically states that *"those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients"* (Truth and Reconciliation Commission of Canada, 2015). The research described in this thesis includes collaboration with Indigenous people with living experience of dementia to improve sustainable and Indigenous-led initiatives for improving dementia care.

There is a paucity of published information regarding Indigenous experiences of dementia care. This gap can result in a lack of guidance for best practice and may

negatively affect the structure and quality of care they receive. There is also little published information on how Indigenous people experience and navigate dementia within a care system. Therefore, the aims of this research are to:

1) Gain an understanding of the experiences of dementia with Indigenous people living with dementia, their care partners, families, and communities

2) Determine the foundational principles of culturally safe approaches to Indigenous-centred dementia care

1.3 Organization of Thesis

This introduction has positioned me in the context of Indigenous health research and positioned the research study in the context of a lack of information regarding Indigenous-centred interventions for dementia. Chapter 2 includes a literature review describing how dementia is defined and understood from a biomedical perspective, what the landscape of dementia and dementia care looks like in Canada, the current rates and landscape of dementia and dementia care among Indigenous Peoples living in Canada, anti-Indigenous racism in health systems, and culturally safe dementia care. Chapter 3 will detail the methodology of Keeoukaywin (The Visiting Way) (Gaudet, 2019) and the interconnection of the methods and analysis, as well as provide space for reflexivity. Chapter 4 will present the results of the study and the framework in which Indigenous-

centred dementia care can be modelled on the experiences of Indigenous people living with and knowing dementia. The discussion presented in Chapter 5 will contextualize the results within the current literature and describe implications and considerations for future research.

2.0 LITERATURE REVIEW

The literature review begins with a description of how dementia is defined and conceptualized, then states the current prevalence of dementia in Canada, western perspectives about the condition, and prevention and treatment options. I detail the current literature describing how some Indigenous people know and experience dementia, and the overarching anti-Indigenous racism born from the colonial and white supremacist systems that formed the health care systems that operate in Canada. Finally, this chapter will conclude with an exploration of the concept of culturally safe care and the current state of dementia care in Canada.

2.1 Dementia Definitions

Western neuromedical models define dementia as an incurable condition that results in progressive changes in cognitive ability that affect memory, coordination, attention, language, planning, and changes in mood or behaviour (Arvanitakis & Bennett, 2019; Government of Canada, 2024). Symptoms can also include decreased coordination, bladder control issues, difficulty walking, standing, or sitting, and stiff muscles (Alzheimer Society of Canada, 2024b; Canadian Institute for Health Information, 2023; Government of Canada, 2024). These symptoms and manifestations of dementia often affect day-to-day

functioning for the individual living with dementia (Alzheimer Society of Canada, 2024b; Canadian Institute for Health Information, 2023; Government of Canada, 2024).

2.2 Types of Dementia

Several types of dementia have been identified and the most common types include Alzheimer's dementia, vascular dementia, frontotemporal dementia, and Lewy Body dementia, or mixed dementia in which symptoms of at least two types of dementia occur (Alzheimer Society of Canada, 2024b). Young-onset dementia is also a common form of dementia that can include the types of listed above and specifically occurs in people under the age of 65 (Alzheimer Society of Canada, 2024b; Thorsen et al., 2020). Young-onset dementia presents distinct challenges for individuals living with the condition including stage-of-life considerations, financial decisions, being a parent, access to support and care, and social connections and stigma (Alzheimer Society of Canada, 2024c) . A non-exhaustive list of other types of dementia can include those caused by other medical conditions such as severe vitamin B insufficiencies, HIV-related neurocognitive disorders, chronic alcohol abuse, and profound psychiatric illness (Gale et al., 2018).

2.3 Diagnosis and Treatment

Due to a range of causes, dementia can be a complex and variable condition that can be difficult to diagnose and manage (Alzheimer Society of Canada, 2024b; Canadian Institute for Health Information, 2023; Constantinescu et al., 2018; Government of Canada, 2024; Magdy & Hussein, 2022). In primary care settings, where health services target initial diagnosis, care, treatment and referrals to other health care providers (Alberta Health Services, 2024), Fernandes et al. (2021) found that although dementia screening tools are available, health care workers in these settings often lack the time to administer diagnostic screening tools to patients. Parmar et al. (2014) found that the most common symptom that triggered a referral to a specialist service were symptoms of memory loss or behavioural difficulties, but other symptoms such as personality changes or functional declines were less likely to result in a referral. Racism experienced by ethnic and racial minorities also affects timely dementia diagnoses and comprehensive evaluations (Kawas et al., 2021), and ethnic minority populations are often not represented in dementia clinical trials which leads to greater health disparities (Babulal et al., 2019). Although dementia can be challenging to manage clinically (Parmar et al., 2014), treatments for management range from medications (cholinesterase inhibitors, monoclonal antibodies, β-secretase inhibitors, anti-tau, anti-amyloid, and anti-inflammatory drugs) to cognitive training, exercise, and physical activity. To treat mood and behaviour changes, social and sensory treatments have also been integrated such as massage therapy, art and music

programs, social programs like book clubs and intergenerational social activities, and animal assisted therapies (Government of Canada, 2024; Livingston et al., 2020).

2.4 Risk Factors and Prevention

Dementia risk factors are often categorized as modifiable and non-modifiable. Non-modifiable risk factors include age, sex, and genetics, whereas modifiable risks are defined as risks that can be potentially controlled by individuals. (Government of Canada, 2024). Modifiable risk factors often include education attainment levels, smoking status, alcohol use, prevention of traumatic brain injury, increased physical activity, and management of chronic health conditions such as hypertension, obesity, and diabetes (Government of Canada, 2024). It is important to note that many modifiable risk factors are "*non-medical, social and economic factors*" (Alzheimer Society of Canada, 2024b, p. 16) that are described as social determinants of health that can affect dementia risk. The degree to which these determinants can be altered is variable across individuals, and includes factors such as income, social status, gender, race or ethnicity, environmental conditions, and access to health services (Alzheimer Society of Canada, 2024b).

2.5 Social Considerations

The effects of dementia reach far beyond the underlying pathology. It is important to consider individual perceptions and narratives which accompany the condition and its impact on autonomy and quality of life (Castano, 2020). The lived experiences of dementia can involve a loss of identity and independence from the symptomatic progression of condition as well as the harmful aspects of social stigma (Reid et al., 2023). The mention of dementia can elicit a strong fear response which can be extremely stigmatizing. I have experienced people visibly recoil when I have described this project to them, and they have told me that a diagnosis of dementia would be "*the worst thing in the world*" and that they would "*rather die*" than have to experience dementia themselves. Western perspectives also problematize dementia (Hulko, 2009) and a diagnosis of Alzheimer's disease and related dementia often means the individual moves from being viewed as a person to being identified as a patient with a pathologized diagnosis (Bottenberg, 2021). There are also deeply embedded social narratives about the capabilities of people living with dementia regarding their contributions to society, or their usefulness, which add to increased stigma and marginalization (Beard & Neary, 2013). The effects of stigma dehumanizes people living with dementia, and can lead to severe disruptions in the social lives of both care partners and individuals living with dementia (Kotwal et al., 2024).

2.6 Dementia in the Canadian Context

The vision for Canada's Dementia Strategy is described as "*a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated*."(Public Health Agency of Canada, 2023, p. 8). The report focuses on dementia prevention, the advancement of therapies and cures, and the improvement of the quality of life of both care partners and people living with dementia, with the overall goal of well-being (Livingston et al., 2020). In January 2024, the prevalence of dementia in Canada was estimated to be 733,040 individuals, with an expectation that this number will rise to approximately 1 million individuals by 2030, and 1.7 million individuals in 2050 (Alzheimer Society of Canada, 2024a). Statistics from Public Health Agency of Canada (Canadian Institute for Health Information, 2023) show that in Canada, women are 1.3 times more likely to be affected by dementia than men, and that the dementia prevalence is 25% higher for individuals 85 years and older. The age-standardized prevalence of dementia in Canada is 6.8%, similar to the provincial prevalence in Alberta which is 7.0%.

2.7 Dementia and Indigenous Peoples

2.7.1 Statistics and Prevalence

Indigenous Peoples within a Canadian context are comprised of First Nations, Inuit, and Métis people. Indigenous Peoples are richly diverse with over 70 languages, 600 First Nations, at least 50 communities of Inuit people, and another one-third of Indigenous people in Canada identifying as Métis (Statistics Canada, 2022). It has been well established that Indigenous populations in Canada experience greater overall health inequities, when compared to non-Indigenous populations (Bowker et al., 2022; Gracey et al., 2009), and Indigenous Peoples in Canada, the United States, and Australia are developing dementia at disproportionately higher rates than non-Indigenous peoples due to the ongoing effects of colonization which impact both modifiable and non-modifiable risk factors for developing dementia (Jacklin et al., 2013; Li et al., 2014; Smith et al., 2008). There is little prevalence data available on dementia rates among Inuit and Métis people (MacDonald, 2018), but rates of dementia amongst some First Nations groups are reported to be up to 34 percent higher compared to the general Canadian population (Canada, 2019; Jacklin & Walker, 2020).

There is likely an underreporting of dementia prevalence for Indigenous Peoples due to the colonial structure of medical reporting systems. There is a lack of Indigenous input into the creation of these databases, and administrative health data collection does not routinely differentiate First Nations, Inuit, and Métis populations (Walker & Jacklin, 2015). Additionally, these datasets do not reflect the data governance and collective rights of First

Nations, Inuit, and Métis Peoples and are not always designed to adhere to the principles of OCAP® (ownership, control, access, and possession), the Principles of Ethical Métis Research as outlined by the National Aboriginal Health Organization (National Aboriginal Health Organization, 2010) and the National Inuit Strategy on Research (Inuit Tapiriit Kanatami, 2018).

2.7.2 Health Outcomes

Indigenous peoples face many barriers in accessing care for dementia. Diagnostic tools are often not culturally appropriate (Pitawanakwat et al., 2016), specialized care services for dementia are often located in urban centers (MacDonald, 2018; Ody et al., 2022), creating challenges for those who live in rural settings. For Indigenous people living in urban centers, the care offered is often not culturally safe. These barriers can result in a delay of dementia diagnosis and treatment, resulting in poorer health outcomes and decreased quality of life (MacDonald, 2018). Despite these alarming statistics and the state of dementia care in Canada with Indigenous people, there remains a lack of published and grey literature on Indigenous conceptualizations and perspectives of dementia and dementia care to inform best practice (Jacklin et al., 2013).

Dementia is considered an emerging health concern for Indigenous populations first because there is a lack of prevalence data for many Indigenous communities and second, because the western biomedical model of describing these symptoms, or

recognizing memory loss as a possible illness may not have the same emphasis by Indigenous Peoples (Bottenberg, 2021; Chiovitte & Jacklin, 2020; Webkamigad et al., 2020). Western health services are only just starting to develop an understanding of dementia informed by both cultural knowledge and biomedical descriptions, and it is imperative to recognize how this affects the understanding of dementia, treatment planning, and care models to appropriately address this condition with Indigenous people living with dementia (Jacklin & Walker, 2020).

2.7.3 Social Determinants of Health and Colonialism

Social determinants of health consist of environmental, societal, and socioeconomic causes of ill health (Czyzewski, 2011), and only when illness is understood within the context of these factors can health and well-being be addressed, and proper supports be made available (Alzheimer Society of Canada, 2024b). It is essential to understand the ways in which social determinants of health influence the health and well-being of Indigenous people not only because lifetime stress accumulation increases the risk of neurodegenerative disease, but because the emphasis on modifiable risk factors for dementia prevention exist outside of the control of many individuals (Alzheimer Society of Canada, 2024b). The root causes of many conditions that affect Indigenous people's determinants of health are due to the ongoing legacy and structures of colonialism (Czyzewski, 2011; Paradies, 2016). Historical and intergenerational trauma are a product of the colonial system and result in detrimental health outcomes (Paradies, 2016).

Colonial systems and structures fueled disempowerment, land dispossession, forced cultural changes, mandatory attendance in residential schools, marginalization, and displacement and removal from families (Paradies, 2016). Colonial systems have permitted the operation of racism, oppression and discrimination that has driven a distinct divide between Indigenous and non-Indigenous populations (Czyzewski, 2011).

In a mini scoping review Henderson et al. (2024) examined both structural and cultural drivers of Indigenous brain health and cognition. They stress that emphasis must be placed on tackling the systematic and structural causes of ill health created by colonialism while also recognizing the importance of the connection of culture as a protective aspect of brain health (Henderson et al., 2024). Because of this, the current state of dementia care with Indigenous people in Canada urgently needs to be addressed (Bottenberg, 2021).

In order to address the dementia-related needs of Indigenous people the Calls to Action from both the United Nations Declaration on the Rights of Indigenous Peoples (United Nations General Assembly, 2007) and the Truth and Reconciliation Commission of Canada (Truth and Reconciliation Commission of Canada, 2015) were considered. The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) under Article 24 states that "*Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services."* (United Nations General Assembly, 2007,

p. 18) and that "*Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right*" (United Nations General Assembly, 2007, p. 18)

In 2015, the Truth and Reconciliation Commission of Canada released 94 Calls to Action for all levels of government, organizations, and individuals to make societal changes to work towards reconciliation. The health-related Calls to Action, specifically, numbers 18, 19, and 22 were considered when examining the original aims of the research. Detailed descriptions can be seen in Table 1.

Table 1: TRC Related Calls to Action

Truth and Reconciliation Commission of Canada: Relevant Health Related Calls to Action
18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.
19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long- term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.
22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

2.7.1 Racism in Health Systems

Canada's current health system is a direct result of colonization efforts; therefore, it is inherently racist (Haynes et al., 2021; Lux, 2016; McLane et al., 2021), and there are abundant accounts of anti-Indigenous racism occurring in the Canadian health system (Lafond et al., 2021). According to the *In Plain Sight Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care Addressing Racism* report (Turpel-Lafond, 2021), the Canadian government's creation of a segregated healthcare system and the racist assumption that Indigenous peoples were somehow lesser or inferior to non-Indigenous peoples resulted in forced experimentation for medical research purposes and the failure to provide adequate healthcare services to Indigenous people. The same report states that Indigenous individuals faced shock therapy, forced sterilization, neglect, stereotypical assumptions and that many Indigenous people do not feel safe interacting with medical services and staff (Turpel-Lafond, 2021).

There is quantifiable data available that shows there is racism in Canadian medical systems. McLane et al. (2022) described how First Nations people accessing emergency rooms in Alberta had lower odds of receiving higher emergency triage scores than non-Indigenous people in the same emergency rooms with the same symptoms. This suggests that Indigenous individuals' presenting signs and symptoms are perceived as less severe, resulting in longer wait times in the emergency department. McLane et al. (2021) determined that First Nations persons relied more heavily on emergency rooms rather than primary care services, and that First Nations people often left the hospital before

completing treatment. For maternity care, Smylie and Phillips-Beck (2019) routinely encountered Indigenous women who were afraid to seek prenatal care because of the racism they had previously experienced, and the fear that their children would be removed by social services.

It is abundantly clear that racism continues to operate in medical systems, including implicit and explicit anti-Indigenous bias that extends from medical school applicants to physicians (Roach et al., 2022; Roach et al., 2023) and that this leads to Indigenous people being unsafe accessing health care. Data from the Coroner's Office of Quebec (2021) showed that the racism Indigenous people experience in the health care system is not innocuous. Joyce Echaquan was a 37-year-old mother of seven children from the Atikamekw community of Manawan in central Quebec who was hospitalised on September 26, 2020, with severe epigastric pain. Joyce died less than two days later after her admission to hospital. The coroner's inquest concluded that "*the racism and prejudice that Mrs. Echaquan faced was certainly a contributing factor to her death*" (Coroner's Office of Quebec, 2021, p. 15). This is only one example of many of Indigenous people seeking care and dying from the racism inherent in Canadian medical systems. The Canadian Medical Association has now formally apologized for anti-Indigenous racism in health care which is evidence that this racism is widely acknowledged (Canadian Medical Association, 2024).

2.7.2 Culturally Safe Care

Defined only by the Indigenous individuals who are accessing health services, cultural safety "*does not profile or discriminate against the person but is experienced as respectful, safe and allows meaningful communication and service. It is a physically, socially, emotionally and spiritually safe environment, without challenge, ignorance or denial of an individual's identity*" (Lafond et al., 2021, p. 11). The introductions of required education to ensure culturally safe care arose when trying to address health inequities among Māori people in New Zealand (Papps & Ramsden, 1996). The implementation of cultural safety education has been shown to mitigate power imbalances between providers and patients (Webkamigad et al., 2020). The impetus being that the prejudice and assumptions that frontline nurses felt against Indigenous individuals could negatively impact the care these individuals received (Papps & Ramsden, 1996), as described in the previous section, and remains a major issue in healthcare systems to the present day.

Other terminology has arisen which is important to clarify, as they are often conflated. Cultural sensitivity or cultural awareness considers "*having knowledge about cultural [diversity] but, more specifically, ethnic diversity.*" (Papps & Ramsden, 1996, p. 495) and merges culture with ethnicity. Cultural competence can be defined as "*the ability of individuals and institutions to effectively deliver health care services that meet patients' socio-cultural and linguistic needs*" (Smith et al., 2022, p. 1) . Cultural humility involves internal self-evaluation and infers a commitment to lifelong learning (Tervalon & Murray-García, 1998). The acknowledgement of being a humble learner and admitting what one

does not know is the foundation in which cultural safety can be built upon (First Nations Health Authority, 2016). Cultural safety specifically focusses on the aspect of 'power' that causes inequities in health, and challenges health care providers to understand the roles they perpetuate that lead to bias, as well as their complicity in upholding colonial structures and outcomes (Smith et al., 2022) and therefore is the term used in this thesis.

2.7.3 Culturally Safe Dementia Care

The consideration of cultural safety is important in the context of dementia care where cognitive decline can increase vulnerabilities to power imbalances (Chakanyuka et al., 2022). The literature regarding culturally safe dementia interventions designed for Indigenous people is relatively sparse, but it is apparent that adapting mainstream dementia care practices into Indigenous-centred dementia care frameworks may attempt to increase health equity (Chiovitte & Jacklin, 2020). Jacklin (2020) describes how effective strategies for dementia care must be community-based in order to be culturally relevant, and that paying close attention to holistic aspects of health will be key for designing appropriate interventions.

There is also information on culturally grounded health literacy and the development of health promotional materials with Indigenous communities. The recent adaptation of a culturally appropriate diagnostic tool, the Canadian Indigenous Cognitive Assessment has helped address barriers to dementia diagnosis (Pitawanakwat et al.,

2016) but implementation of Indigenous-centred dementia care models in practice continues to be challenging. Ensuring that Indigenous dementia care interventions are culturally safe is critical to addressing health inequities, however, focussing solely on cultural safety leaves an important gap that needs to be filled. The research described in this thesis aims to fill this gap by shifting the emphasis from cultural safety to also involve cultural humility. Understanding the experiences of individuals living with dementia, their care partners, families and community is the first step to creating an Indigenous-specific dementia intervention that links Indigenous-centred care onto existing western frameworks of person-centred care (Kitwood, 1997).

Chapter Two Summary

This chapter has described how current understanding and interventions of culturally safe Indigenous-centred dementia interventions is not meeting the needs of Indigenous people. More research is necessary to gain an understanding of the experiences of dementia for Indigenous people living with dementia, their care partners, families, and communities. In the following chapter, I will describe the methodology and methods used for this project.

3.0 RESEARCH METHODOLOGY AND METHODS

In this chapter, I will describe the methodology used for my thesis and my relationship with this methodology. I will detail the study design and methods including information on participant sampling, recruitment, data collection, and analysis. I will describe rigor and how it was ensured. To reiterate, the purpose of this study is to create a foundation for a framework to enhance Indigenous-centred dementia care. and the specific aims of the research questions are to:

1) Gain an understanding of the experiences of dementia with Indigenous people living with dementia, their care partners, families, and communities

2) Determine the foundational principles of culturally safe approaches to Indigenous-centred dementia care

3.1 Philosophical Orientation

The philosophical orientation of this project is grounded in an Indigenous worldview and informed by Indigenous paradigms (Wilson, 2003) According to (Wilson, 2003, p. 161), "*Everything needs to be seen in the context of the relationships that it represents*". In the Indigenous Health Leadership course I completed during my graduate training, we were presented with a webinar by Shawn Wilson in which he described non-Indigenous

researchers doing good Indigenous-based research as adopting an Indigenist lens when doing research, similar to how one may use a feminist lens. Having been raised in a predominantly western system with a colonialist lens, unlearning these habits was integral in understanding an Indigenous worldview orientation. By grounding myself in Indigenous paradigms, Indigenizing western methodologies (Smith, 2021), and *"placing Indigenous knowledge at the forefront for understanding and using theories based on Indigenous viewpoints and needs*" (O'Keefe et al., 2018, p. 777), I have been acknowledging the merit that these worldviews hold on their own without comparing them against western systems. This creates a tension while still having to function within an academic system that values western ways of thinking and doing as the valid and only ways of thinking and doing.

By embracing an Indigenous paradigm, I have come to relate to the interconnectedness of ontology, epistemology, axiology, and methodology as described by Wilson (2008). He connects what is real (ontology) and how we know what we know (epistemology) as the relational aspects of the Indigenous paradigms. He then describes the ethics and morals that guide the research (axiology) to how the knowledge is gained (methodology) as connected to accountability. Relationality and relational accountability are key when engaging with Indigenous people in research, especially for non-Indigenous researchers. This means that an Indigenous research paradigm is tied to the relationship between the research participants' experiences and ideas, and the relationship between the researcher, Indigenous communities, and research participants (Wilson, 2008). The validity and reliability of this study exist within the relationality of the research, and

ensuring the research reflects the true voices of the participants is how I demonstrate my accountability to those who have shared their stories.

3.2 Methodology

Methodologies comprise the "*theoretical positions and perspectives and involves thinking through method, data collection strategies, analysis techniques, and the production and presentation of findings*" (Mayan, 2009, pp. 30-31). While this sounds like a linear process, Kovach states "*Indigenous methodologies require exploration of identity, an ability to be vulnerable, a desire for restitution, and an opening to awakenings*" (Kovach et al., 2018, p. 217). With this in mind, she describes how one cannot simply 'do' Indigenous methodologies. She outlines that Indigenous epistemology, i.e. "*beliefs about the scope and nature of knowledge*" include four important points:

- "Knowledge is holistic and implies empirical, experiential, sensory, and metaphysical possibilities,
- Knowledge arises from interconnectivity and interdependency
- Knowledge is animate and fluid
- Knowledge arises from a multiplicity of sources, including nonhuman sources" (Kovach et al., 2018, p. 218)

Attempting to surround myself with Indigenous ways of knowing, doing, and being has been a constant learning experience. Having been raised within systems that seek to actively repress many of the points included in Kovach's scope of knowledge I will admit that it has been difficult to know how to engage in a relationship with the methodology used. However, I mention this not as a negative point or as a limitation, but as a strength. I attempted to challenge the colonial ways of knowing and doing research by sitting with any discomfort I felt, writing about it, discussing with colleagues and with family members. For example, at one point after several interviews I was becoming anxious that I wasn't asking the perfect questions that would lead to some kind of revelatory answer. I realized that the attempted pursuit of the 'right' answer is antithetical to engaging with Indigenous methodologies. I took time to uncover this discomfort and realized that by allowing participants to express themselves openly and honestly without an agenda, and by sharing pieces of my journey, I was actually sharing myself and participating in someone’s life which is foundational to the methodology I was engaging with for this project.

3.3 Keeoukaywin (The Visiting Way)

"*There is a certain amount of self-responsibility to come*

face-to-face with what and where we are."

Gaudet (2019, p. 59)

Keeoukaywin is a methodology rooted in Métis and Cree ways of being, with relationality at the core (Gaudet, 2019), which is deeply connected to Wilson (2008)'s notions of relationality as fundamental to human connection. Gaudet describes how visiting is not just about the act of sitting down with another human being, visiting is listening, reading, immersing yourself, situating yourself, and reflecting with all things (Personal Communication, Nov 22, 2023). I have tried to carry this with me throughout my thesis project and it has felt like a constant balance between shying away from an Indigenous methodology because I am a non-Indigenous researcher and remembering that I have been invited to do this research in a good way, led by good people. Gaudet (2019, p. 53) states that this methodology is a "*way of remembering our voices, stories, struggles, responsibilities, and each other*." and so my responsibility as a non-Indigenous researcher engaging with Indigenous research is to amplify those voices, stories, and struggles and uphold my relational responsibilities. In Gaudet's essay, she describes how Keeoukaywin is a living practice involving, "*respect for the past and present, and a means of its own continuation into the future*" and "*is concerned with both the feelings you leave with, and the feelings you leave behind*." (Gaudet, 2019, p. 57). With this reminder I have continued

to visit with my positionality in this research, and with the participants who shared their stories.

The ultimate goal of this research is to create an understanding that is useful to the participants involved in the research (Green & Thorogood, 2018). Indigenous people consistently face harmful research practices that extract data without returning results or change back to the community. These practices frequently include 'health equity tourism' where underlying social determinants of health are ignored for the sake of plentiful publications, often on topics such as disease prevalence (Lett et al., 2022). These harmful research relationships have had detrimental effects on Indigenous people (Goodman et al., 2018). This study involved participants at all levels of research design and execution which was purposeful for preventing harm, and an active way of engaging with an Indigenous methodology.

3.4 Study Design

3.4.1 Sampling and Recruitment

The inclusion criteria for this study was broad and comprised of Indigenous persons living with any type of dementia, family members or care partners of an Indigenous person living with dementia, or Indigenous community members who has experience with dementia. Individuals living with dementia were invited to participate in the interview

process regardless of the severity of dementia. All potential participants also needed to be over the age of 18. Participant sampling was done by purposive and snowball sampling to ensure research participants were specifically targeted to answer the research question and to recruit individuals by word of mouth from previous participants (Creswell & Poth, 2018). The initial target number of participants was 15 individuals, which was more than adequate for a qualitative study (Hennink & Kaiser, 2022).

Through ongoing relationships with community partners, recruitment was completed through online advertising on social media including X (formally Twitter) and Facebook, and through Indigenous community newsletters and urban Indigenous programs for seniors and Elders (appendix A). Individuals who were interested in participating in the study contacted our research team via email (appendix B). Historically, community partnerships have been overlooked and harmed as a result of extractive research practices (Lett et al., 2022). Recruitment through community partners enhances the relationships and reciprocity between researchers and community partners and ensures that the research is reflexive of what communities are asking for. Relationships with the community partners we work with are ongoing, with involvement in multiple projects, ensuring sustainability for those we are co-researching with.

3.4.2 Consent and Capacity

Informed consent was obtained from participants prior to any study activities, with attention paid to the intricacies of consenting people with cognitive issues and understanding that capacity can be variable or situational (Rivett, 2017) (appendix C). Oral consent forms were used for participants interviewed over Zoom or the phone (appendix D). Consideration of participant autonomy while balancing the ability to provide informed consent was upheld by continuously checking for decision-making capacity on multiple occasions prior to, during, and after the interview process (Murphy et al., 2015). Historically, the voices of people with dementia have been excluded from dementia research (Dewing, 2002; Murphy et al., 2015). Due to the ethical responsibilities of the researcher, obtaining informed consent from people living with dementia can be problematic, often leading to exclusion (Dewing, 2002). Hellström et al. (2007, p. 611) suggests that "*the capacity to consent should be judged primarily in terms of what the person is being asked to do*". The informed consent processes for research activities such as an interview about someone's experiences of dementia may not carry the same weight as informed consent for a clinical trial, however, they are often treated equally in terms of ethics protocols. For this study, following the process consent method (Dewing, 2002) , special attention was paid to the biography and history of the person with whom consent was collected. Understanding the individual's baseline well-being helped to inform instances when informed consent may not have been possible. To further enable continued participation for individuals who may have had cognitive impairments, the

consent form and interview guide were written in accessible language and avoid stigmatizing descriptions of cognition (Rivett, 2017).

3.4.3 Role as the Researcher

The role I assumed in this research was as a supportive listener. As I had previously learned in my earlier research experience, the researcher holds power over participants. I attempted to mitigate this power imbalance by being upfront about my non-Indigenous identity, the intent of the study, and that I was early in my research about these topics. I found that I was able to connect with each individual on a personal level which increased feelings of trust and overall humanity and relationality. Establishing rapport with participants is incredibly important for the research process, and more importantly, to build a relationship. I personally engaged participants in discussions that were deeper than just chatting about the weather such as asking about their plans for the day, or, depending on the information shared with me previously, asking about their families to establish a connection with each person. Whenever possible, I offered to bring coffee and donuts for a positive introduction. I ensured that people were comfortable with the location we were interviewing in, and tried to mitigate any inconveniences they may have experienced while taking time out of their busy lives to talk with me. For example, some

participants did not want to meet at their homes and preferred to meet in public, whereas some preferred I came to their home. I also offered interviews over Zoom if it was more convenient.

3.5 Data Collection

After contacting the research team, participants were sent an electronic copy of the consent form. Prior to the interview starting, I ensured participants understood the ethical aspects of the study and provided either a signed informed consent form or we completed explicit oral consent using a script approved by the research ethics board. Participants were given a $100 honorarium for taking part in the interviews which was given in cash if the interview took place in person, or via e-transfer. A general interview guide was used (appendix E) and probing questions related to the stories people told in response to the initial interview questions were used as needed. Sample questions from the interview guide include:

- What is your experience with dementia?
- What does "*dementia*" mean to you?
- What kinds of things are important to you if you have dementia, or if you have a friend or relative with dementia?

The interview guide was developed in consultation with the research team, which included researchers, clinical experts, health systems leaders, Indigenous advisors, community partners and Indigenous people with lived experience of dementia. After the first two interviews, it was determined by this diverse group of experts that no changes were needed. With participant permission, interviews were recorded on a digital audio recorder to be transcribed.

Three interviews were transcribed by me to familiarize myself with the process of data transcription, and to immerses myself in the data. After these initial transcriptions, the remaining interviews were transcribed by Rev.com, a transcription service approved by the Research Ethics Board to produce verbatim transcripts. The transcripts were then read, verified and anonymized by me before being imported into NVivo in order to manage the data analysis (NVIVO, 2018). Participants were invited to choose pseudonyms for themselves. Additional pseudonyms were assigned by me to any other names mentioned in participant responses to preserve anonymity but also to give context to the quotes and to maintain personhood of family members or care partners. Participant quotes are presented verbatim except for minor editing for spelling and readability. During the project I kept field notes on each interview in a notebook and all notes were only identified by participant number and were in no way identifiable. Personal reflexivity notes were kept using the web-app, Notion. These notes were not about participants, but more related to my positionality and questions or thoughts about the research process to reflect on. No

identifying participant information was stored anywhere but the encrypted University of Calgary shared drive.

3.6 Data Analysis

Thematic content analysis was completed to illustrate key elements that are alike and varied among the accounts of participants (Green & Thorogood, 2018). Thematic analysis is a useful method to find evidence for a specific research question, or set of research questions (Green & Thorogood, 2018). However, it is important to keep the context of the quotes preserved as cherry-picking without context does a disservice to the research and to the participants. Although summarization and grouping concepts together is important, keeping the context of an individual's experiences is also imperative. Ensuring that the data is true to the participants is part of relational accountability (Wilson, 2008).

The steps to thematic content analysis include familiarization of the data, the identification of themes, creating codes, and further organizing the codes into themes (Green & Thorogood, 2018). All transcripts were reviewed and read multiple times before coding began because full immersion in the data was essential for a complete overview and understanding of the content. To initiate coding, anonymized transcripts were imported into NVivo (NVIVO, 2018). Transcripts were read in full, and descriptive codes

were generated by doing line-by-line coding. As codes developed, notes were made to re-read past transcripts for related data. Once all transcripts were initially open-coded, I went back to the first participant and re-coded using the more complete codebook as well as my field notes. Once I was unable to generate additional codes from the data, the codebook and random transcript samples were sent to my supervisor to check for coherence, clarity and association of the coding.

Qualitative interviewing and thematic analysis are useful ways to engage with this data because of the flexible nature of interviewing and the willingness of participants to discuss their experiences (Denzin & Lincoln, 2018). In essence, participants are able to choose what they attach importance to. Once the coding was complete and the framework was drafted, a research summary was sent to participants and the project team for feedback and to ensure the findings aligned with participants experiences. This relates back to Keeoukaywin as a methodology because I was, quite literally, visiting with the data. Both Gaudet (2019) and Wilson (2008) describe the importance of accountability to the participants and the data and I have shown this with the transparency of my coding and the inclusion of participant quotes.

3.7 Ethical Considerations

As the study aimed to reach diverse Indigenous populations, the principles of OCAP™ (First Nations Information Governance Centre, 2014) the Principles of Ethical Métis

Research as outlined by the National Aboriginal Health Organization (National Aboriginal Health Organization, 2010) (NAHO) and the National Inuit Strategy on Research (Inuit Tapiriit Kanatami, 2018) were the guiding principles for ethical engagement for research with distinct Indigenous communities. The proposed work also respected the principles of sovereignty, self-determination, and reciprocity (Wilson, 2008). To engage with relationships, my team and I attended a Culture Camp with one of our community organizations which involved teachings, feasts, and visiting. We also participated in pipe ceremonies and tipi raising with another community organization. To ensure an integrated knowledge translation approach we established an advisory group consisting of co-researchers and advisors. We invited people living with dementia, as well as potential family and care partners, Indigenous community members, Elders, health care providers and researchers. This group was involved prior to the start of the research and during all phases of the study. By inviting these people to take part in the advisory group we ensured the research was reflecting community needs and upheld ethical ways of doing Indigenous research. This project was also approved by the Conjoint Health Research Ethics Board at the University of Calgary (REB22-1413).

3.8 Rigor

Describing specific indications of rigor are important to ensure the research is trustworthy (Creswell & Poth, 2018; Lincoln & Guba, 1985). Lincoln and Guba (1986) suggest parallel criteria for ensuring rigor in qualitative studies including credibility,

transferability, dependability and confirmability. The indicators of rigor in this study align with these parallel criteria. To ensure credibility, interviews involved intensive contact through visiting and adapting to participant behaviors and navigating social situations. Special attention was focussed on novel experiences or descriptions. Peer debriefing also took place with a colleague working on related research projects within our research team after each interview, while maintaining confidentiality of the participant. Member checking was done by sending out project summaries to the participants to ensure the data was representational of their experiences. Clarification during the interview was also asked for if any statements were confusing. For transferability, thick descriptive data (Geertz, 1973) were used to create a framework for Indigenous-centred care, and examples of coding and context have been included in the results which also enhances dependability. Confirmability has been attempted through reflexivity and openness with my personal history and motivations for engaging with this research.

Chapter Three Summary

This chapter has provided detail on the foundational methodological ideas and how data were collected for this research. Chapter 4 will describe the findings of this research as well as a framework for developing high-quality Indigenous-centred dementia care grounded in lived Indigenous experiences of dementia.

4.0 FINDINGS

This chapter will describe the findings from the study. I will present a framework for Indigenous-centred dementia care that is informed through thematic analysis of participant experiences and followed by consultation with the project team and the project group of advisors. The descriptions of the overarching themes of relationality, being well, and safety set within subthemes of cultural, physical, and social experiences are integral for consideration and creation of an Indigenous-centred dementia care approach. Each theme is presented and defined with its corresponding subtheme (cultural, physical, social).

4.1 Demographics

Detailed participant demographic information can be viewed in Table 2. Participants were encouraged to provide a pseudonym of their choosing. A total of twelve participants were recruited and interviewed, with diverse experiences of dementia impacting their lives. Most of the participants were female (n=9). Participants were asked what their gender identity was, and data was captured accordingly. Participants did not specifically mention if they were cisgender, and this information was not asked by me. Most of the participants identified as Métis (n=8). One participant identified as non-Indigenous, but her experiences were in connection with her Indigenous partner who was living with dementia, which the team felt was an important and relevant experience to

include. Participant ages ranged from 26 to 84 years, with a median age of 46.5 years. Interviews began on September 1st, 2023, and ended on January 12th, 2024. Seven interviews were conducted over Zoom/Phone and five were conducted in person. Interview lengths ranged from 10 minutes to 84 minutes with the median duration being 55 minutes. For one participant, the interview was ended because I could tell he was becoming uncomfortable. His answers became shorter, and he would redirect questions I asked with "*Yeah*. *Anyway*.". He gathered up the consent documents and asked if they were his to take, so the interview was ended.

Table 2: Participant Demographics and Interview Details

DEMOGRAPHICS				INTERVIEW DETAILS			
Name	**Gender**	**Indigenous Identity**	**Age**	**Experience**	**Date**	**Location**	**Duration**
Zoe	Woman	Métis	35	Health care worker	2023-09-01	Zoom/Phone	66 min
Lee Marie	Woman	Métis	65	Health care worker and care partner for parent	2023-09-04	Zoom/Phone	67 min
Alice	Woman	Métis	26	Health care worker	2023-09-07	Zoom/Phone	39 min
Irene	Woman	Cree	66	Care partner for spouse	2023-09-08	In Person	71 min
Robert	Man	Métis	84	Person living with dementia	2023-09-08	In Person	10 min
Sophia	Woman	Non-Indigenous	68	Care partner for Indigenous spouse	2023-09-16	In Person	84 min
Nora	Woman	Métis/Cree/Dene	55	Care partner for aunts	2023-09-17	In Person	37 min
Chloe	Woman	Métis	33	Health care worker and care partner for grandparent	2023-09-18	In Person	48 min
Earl	Woman	Métis/Cree	43	Care partner for parent	2023-10-16	Zoom/Phone	73 min
Edward	Man	Métis/Cree	37	Care partner for parents	2023-11-29	Zoom/Phone	52 min
Thomas	Man	First Nations	32	Care partner	2023-11-30	Zoom/Phone	50 min
Martha	Woman	First Nations	50	Care partner for parent	2024-01-12	Zoom/Phone	58 min

4.2 Framework for Indigenous-centred Dementia Care

Based on the analysis, a framework for Indigenous-centred dementia care is presented. Three main themes are described: relationality, being well, and safety with three subthemes that describe important dimensions to be considered when implementing the framework. These include social, cultural, and physical dimensions subthemes that occur within each of relationality, being well, and safety. These are foundational for the creation of an Indigenous-centred care approach that can specifically target areas to address health inequities. As expected, the realms of consideration are interconnected with each other. For example, you may not be well physically if you are not receiving safe care.

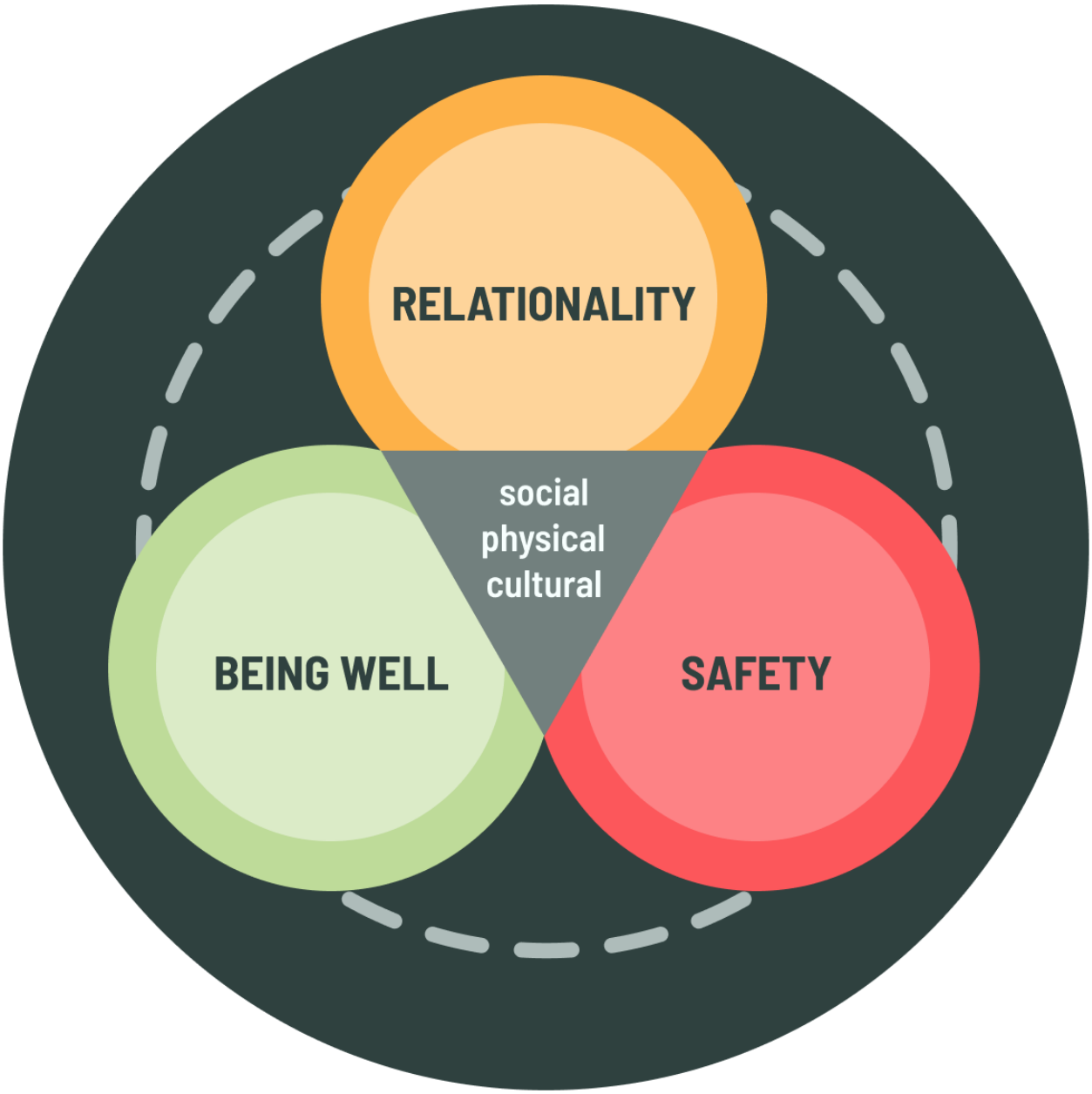

Figure 1. Framework for Indigenous-centred dementia care

4.2.1 Theme 1: Relationality

What is relationality? It is more than just relationships with other people. it relates to the holistic existence and relationship of self, the embodiment of relationships, as well as the external relationships to ideas, which are informed by the specific context (Wilson, 2008). To mitigate the risk of pan-Indigenizing, Table 3 illustrates the analysis process for this theme and presents examples of descriptive codes, corresponding quotes and my theoretical interpretations using field notes for context. After the table I present a more detailed description of the analysis and findings.

Table 3: Process of defining relationality within three subthemes

Theme 1: RELATIONALITY			
Subtheme	**Descriptive Coding**	**Quotes**	**Field Notes**
Social	advocacy, family experiences, burden, grief, family dynamics, relationships, health care	"*You need help so that instead of focusing on the day-to-day care needs, you can focus on your relationship with them*." - Chloe	• *codes nestled under family experience - 16 subcodes* (2024-2-8) •*how relationships and family dynamics impact the health of the person with dementia* (2024-3-6) •*the importance of relationality with health care workers* (2023-9-17) •*Placing self in family history/context* (2024-3-24)
Physical	care facility, built environment, residential schools	"*That's right. There's no mental or physical stimulation at all. They just walk around in a square, bumping into each other, no TV, nothing. Like, there's just nothing*". - Martha	•*the built environment around you affects the connection to yourself* •*how do institutions affect the health of those affected by residential schools?* (2024-4-4)
Cultural	community, person centred	"*He doesn't want anything to do with [culture] anymore. He's disillusioned by it, right?"*- Irene	•*not everyone has a relationship with Indigenous cultural practices - it's about meeting people where they are at* (2024-2-8)

4.2.1.1 Relationality - Subtheme: Social

Social relationality relates to social relationships with others, as well as embodied relationality. Social relationships with others are a key component of relationality for both the person living with dementia, family members and care partners, including healthcare workers. Robert, someone living with dementia, specifically mentioned his relationship with his wife, children, and grandkids:

"*Anyway. Well, [Dorothy] is my girl. She's pretty damn good. Yeah. Anyway. She came along at the right time, I think, in my life, eh?"...And [my son], he's got kids and that, eh? So, we're grandparents too. Well, not lots, but I think we got a couple anyway, couple o' kids*."

- Robert [person living with dementia]

When I asked Robert if his memory issues impacted his wife he replied:

"*I don't know because, I don't think it makes her sad, it's just part of life and she's with me, you know?"*

- Robert [person living with dementia]

I was able to appreciate the deep connection between him and his wife as well as the importance he placed on his relationships with his children and grandchildren, although it seemed unclear if he knew the number of grandkids that he had and seemed unaware of how his experience of dementia was affecting his wife.

Irene described her relationship with her longtime husband, Walter, and his transition into becoming more dependent on her when previously she had been more reliant on him.

"*And so, for the last 13 years he's been my rock, in the last two years, I'm his rock*."

- Irene [care partner for spouse]

She also explained the difficulty in aging in general and the realization that her relationship is changing. She was visibly upset during this part of the interview which, I believe, indicates how much the relationship means to her.

" *I think I'm still [in] a little bit of denial. I think a lotta denial really. And heartbreak. 'Cause I'm just realizing our lives are on the next phase and there's gonna be a big change*."

- Irene [care partner for spouse]

The effects of family dynamics came up in multiple interviews, and the participants often arranged themselves within the context of their families, as specifically noted by Earl. This seems central in the context of relationality, and family dynamics are often complicated.

"*I know that nobody else is gonna have this experience, and it's so wild. I'll give you a lot of background information about my family dynamics because it very much plays a part of the current situation*."

- Earl [care partner for parent]

Zoe, a healthcare worker, explained the importance of social and cultural relationality between health care workers and family members of someone experiencing dementia.

"*Yeah, in the last year there's the new Indigenous support line and they've been super great even though it's over the phone, building rapport and helping them feel like they have somebody on their side if you were to say it that way, or vouching for them, that's been really positive*."

- Zoe [health care worker]

Embodied relationality relates to the interconnectedness of body, mind, and identity coupled with the awareness that exists and is grounded in relationships (Coaten &

Newman-Bluestein, 2013). For Lee Marie, the use of her father's name embodied his identity, but she's also frustrated at the lack of relationship between her father and his health care workers who didn't invest in a connection with him.

"*You know, you need to call him by his name," right? His name was [Buddy], and I was like, "You need to call him [Buddy]. He'll know, he'll remember [Buddy]. Talk to him about horses, tell him you brought [the horses] in..."*

- Lee Marie [health care worker and care partner for parent]

During the conversation with Sophia, she described how she preserved some beadwork that her partner had worked on decades before and how she was going to integrate it into a gift for him. She insisted on showing me her sewing room and her projects and talked about how her sewing room was like her sanctuary that she could decompress and ground herself in, but also not have to leave and worry about her partner. Irene described how difficult it was to watch Walter forget things one day, only to remember the next. She jokingly told me that she wanted to ask him if he was faking the memory loss, but then followed up, teary eyed with the quote below describing how the core of Walter was there, even if his day-to-day cognition fluctuated.

"*And there's lots of stuff he [created]. Lots of stuff…But yeah, this is my sanity, basically. When he goes to bed this is where I am, and he's right there beside me [in the next room].*"

- Sophia [care partner for Indigenous spouse]

"*Sometimes your knowledge is gone and it's all your heart. Right now, it's taking a lot of strength out of me just to not forget that."*

- Irene [care partner for spouse]

Chloe described the importance of viewing a person as more than their dementia, back into the parts that bring them into their identity, or the core of who they are. While Edward explained how traumatic dementia is in regard to how you lose a person despite them still occupying their body.

"… having those conversations with them, yes, acknowledging, "Yes you have dementia," but always taking those moments to find hope, and resiliency, and to find ways of kind of lifting them back up into who they are."

- Chloe [health care worker and care partner for grandparent]

"*That is something that I would really emphasize on, because much like any kind of traumatic experience, and the fact that you have someone in your family who has a family member with dementia, it's trauma. There's no doubt about it. There's trauma involved. You lose a person. You lose a person in real time."*

- Edward [care partner for parents]

4.2.1.2 Relationality - Subtheme: Physical

The physical subtheme relates to both the physical person and the spaces they occupy, but also their relationship or connection to their body and mind. Related to the connection with the physical body and the mind, the physical act of a childhood ritual brought Earl's father into relational connection with her, and the importance of this, even though it was brief, is encapsulated within the quote:

"*So, this is like a little routine that we used to always do, is like I would wiggle it, give him a wiggle hug. And then he'd say, "where's your nose?" and then he would kiss my nose. And so, he was kind of… there. Like, he knew who I was. I knew that he knew who I was for a moment, and then he went back to nothing*."

- Earl [care partner for parent]

The connection to a physical space or a built environment was described as important by several participants. Thomas mentioned the atmosphere of a care facility reflecting Indigenous imagery and not feeling institutional. Chloe discussed the importance of a space where the person living with dementia feels engaged and how even seemingly innocuous aspects of a space can be important.

"...rustic kinda older school feel rather than something bougie and gaudy...something that just feels like they're sitting at a cabin that feels comfortable... having Indigenous imagery in there"

- Thomas [care partner]

"*I think the way we're creating buildings needs to change, like I think there's a lot that happens in like the actual bones of a building, right? Even when you walked in here and you commented on our pastel doors... something small like that does something, right?"*

- Chloe [health care worker and care partner for grandparent]

Martha described how many care facilities are devoid of connection to individuals living in them, and when asked if she could have changed any barriers to her mother's living situation she stated:

"*My mom's sitting around in a home where [the residents] don't even have a TV on in there. My mom likes watching westerns. So, to me, being in a home makes them regress even more, if you ask me*."

- Martha [care partner for parent]

4.2.1.3 Relationality - Subtheme: Culture

Relationships with culture were described as an integral piece of relationality. Even when someone may not be connected to Indigenous culture specifically, there can still be cultural aspects that can be important such as beliefs, values, and traditions. For Lee Marie, who hadn't connected with her Métis culture and whose father was in the hospital and had dementia, the connection she felt with Indigenous people in her father's room was invaluable.

"*'cause my dad came with culture. Even though he would not self-identify, he had all the right cultures."*

- Lee Marie [health care worker and care partner for parent]

"*We put the fiddle on for him." (laughs) …and this was my first piece of community coming around, and I don't even know these people*!"

- Lee Marie [health care worker and care partner for parent]

Chloe mentioned that improved relationality would lead to better health outcomes if concerted effort was put in by those working in health care systems. Adding to this, Alice

shared how internal biases from healthcare workers impact the care that Indigenous patients receive.

"*It's the way that we systemically continue to not support, First Nations, and Indigenous cultures, and say that, "No, that is a special thing, no that is something that you can only get over here, it's not something we can integrate into our facility." What? It's not that hard, like these are steps that are not that hard to do, it just takes some concerted effort, and some compassion, and understanding.*"

- Chloe [health care worker and care partner for grandparent]

"*A lot of people, especially some of the more middle age healthcare workers that I've worked with, they tend to still have stereotypes, and it can affect patient care in a negative way even if they don't do anything necessarily illegal. They still provide care, but it's not meaningful care.*"

- Alice [health care worker]

4.2.2 Theme 2: Being Well

What is being well? Being well is situated within a holistic definition of wellness. Being well is deeper than a quantitative scale of measurement of quality of life often seen in a western or biomedical model, it is a state of being that can constantly be in flux

depending on the state of the social, physical, and cultural subthemes. There may be causation within each subtheme. For example, if one is physically unwell, that may affect social wellbeing and vice versa. It is a broader concept than western models of wellness, where being well is not just about attaining physical health, or treating a physical condition, but includes mental, physical, emotional, and spiritual wellness. The analysis process can be seen in Table 4 with descriptive code examples, corresponding quotes and theoretical interpretations.

Table 4: Process of defining being well within three subthemes

Theme 2: BEING WELL			
Subtheme	**Descriptive Coding**	**Quotes**	**Field Notes**
Social	relationships, friends, neighbours, advocacy, pets, community, care partners	*"[the nurse] decided to play cards with my dad in French, so he had his Crib board, and he had cards, because he learnt about this man, and- there again, comes some community to me and I was like, "Wow. This is great for my dad*." - Lee Marie	•*The relationships that occur with the person with dementia ripple out to care partners or family members* (2023-09-01)
Physical	dementia support	"*Oh my god. (laughs) Actually, that's what I need [respite care]. That's what I need. I wonder if there's a way I can get that*". - Earl	•*there is an overwhelming lack of support in some of the day-to-day activities* (2023-10-16) •*parenting your parents* (2024-3-14)
Cultural	traditional, cultural	"*And there's a lot of things where I've really been grounded in some of the teachings and understanding that's been going on, that makes me go, Wow, all this stuff makes sense, and it has helped improve my life. Why wouldn't I have done this earlier?"* - Edward	•*returning to culture* •*culture as preservation* (2024-2-21)

4.2.2.1 Being Well - Subtheme: Social

Social relationships are integral to being well. The importance of relationships that were considered to be healthy and fulfilling were expressed by many participants. They often described the historical complexity and relational aspects of their relationships such as how they fit into their family lineage, or how their parents were located in the family genealogically. They shared how negative family dynamics affected their health as care partners, and how positive relationships were integral to being well. Edward mentioned the cumulative stress that occurs when there is infighting within family members or care partners. Participants also expressed how difficult it was to watch their loved one become confused and not recognize them as their children anymore such as Lee Marie, and for Edward he experienced a compartmentalization of the relationship with his mother from son to care partner. He was very emotional in the retelling of this part of his experience.

"*And now it's caused this additional rift, this additional problem, it's, you know… essentially, ripped the family apart in that regard*."

- Edward [care partner for parents]

"*My dad was like my best friend."*

- Lee Marie [health care worker and care partner for parent]

"He always called me [Cathy], and my name is Lee Marie, and he called me [Cathy] 'cause he had gone back to the farming times- ... and [Cathy], uh, was my cousin... I always corrected him. I told him, "Dad, it's Lee Marie," and it just caused him sadness, it seemed."

- Lee Marie [health care worker and care partner for parent]

"*When there's the degradation of the person, you almost separate them into different people. Like, there's different stages of who the person you're experiencing [is]. And you can't have the same expectations on that person as you did in maybe an earlier version. You know, you have to switch into full caregiver mode."*

- Edward [care partner for parents]

Additionally, Sophia described the collapse of relationships with friends because they did not know how to act around her partner with dementia. She also protected her partner from the pain of his friends cancelling on him by not telling him they planned on coming and didn't show up. There is also a strong feeling of stigma in her statement.

"*But, you know, another thing that I find with dementia? His friends. It's like it's fucking contagious.... They don't come around. And one of his friends phoned about two weeks ago. Well, he was phoning me off and on the last few years, saying, "Yeah. We're gonna come over and visit, and how's [Arthur] doing?" I said..."Well, [Jack], he hasn't got much time. You wanna come see him, you'd better do it now." He goes, "Oh, shoot. Oh, god." And he says, "Okay. I'll be there Thursday." That was last Thursday. He never showed up. And it's a good thing I don't tell [Arthur]*"."

- Sophia [care partner for Indigenous spouse]

Another aspect of being well under the social subtheme is that interactions and activities are meaningful and specific. They go deeper than just surface activities that serve to pass the time. These are social activities and engagements that are an important link to identity and self (Waugh & Mackenzie, 2011). Earl shared her interactions with her father in hospital that were fueled for his passion for music, but also increased their connection in

that moment because it was based in memories from their past when she would play the fiddle, and they would dance.

"*... So, I put on the Red River Jig from my dad, and I was holding his hand, and I was standing up beside his bed. And I was like jigging, like dancing for him and had the music really close to his ear. And he was just beaming. And he squeezed my hand and then he lifted his hand and was like trying to act like he was dancing*."

-Earl [care partner for parent]

After Sophia arranged respite care for her partner, he reacted by saying "*Don't ever bring another man in this house. Ever. And I don't need a babysitter*". She realized that the respite care worker was not engaging with her partner in ways that were meaningful, so the next time respite came she told her partner, *"[Respite]'s here. You have to train him. He's learning some health stuff, and you have to evaluate him*". This gave her partner a sense of purpose and when she came home, she asked what her husband taught the respite worker, and he replied "*electrician*". After this encounter he was able to form more of a relationship with the respite worker, expressing humour and joking with him.

In a health facility setting, Lee Marie described how her father who had dementia had mentally returned to being in a convent being tasked with handling the laundry:

"*He had [gone] back in time somewhere and that he had to do that laundry, and they had him completely strapped down, like he was in a mental hospital. He kept saying 'je dois laver les vêtements' He had to wash the clothes*."

- Lee Marie [health care worker and care partner for parent]

The reaction of the health care workers to employ restraints because Lee Marie's father was wandering on the unit was such an extreme reaction. Lee Marie explained that the health care workers stated, "*we can't watch him*" and she was very upset that something as simple as washing clothes could not have been implemented as a purposeful social interaction for her dad.

4.2.2.2 Being Well - Subtheme: Physical

Being well, physically includes physical health, and the physical aspects that impact quality of life such as fatigue, pain, overall physical functioning, health, sleep quality, and self-efficacy (Cho et al., 2024). Earl described the absolute bottom line stress of managing her household, being a care partner, a parent, and a grandparent and working full time and how that state of being has impacted her.

"*I'm spread as thin as you could possibly imagine…I don't even know what I need. Like, I just don't want to make choices. I don't want to make decisions. … because I'm so in the trenches, I don't even know what I need. I'm just putting out fires."*

-Earl [care partner for parent]

"*I don't really have too many people to talk about it because no one really understands, and, and I know that there's support groups for it. And I just, it's like one more thing to find something to spend my time on and I don't have time for like this. So crazy busy right now*."
- Earl [care partner for parent]

For Thomas, the inability of his grandfather to engage in his usual activities had a direct impact on his cognitive and physical health. He used to golf (walked the course) and curl every day, but his health declined exponentially during the COVID-19 pandemic.

"*Then COVID hit, they were locked in their apartment. We weren't allowed to see them. No one was allowed to see them. And you saw his cognitive decline just straight shoot down, where my grandma's had been slow, slow, slow. So now, his cognitive decline is probably on par - probably a little better than my grandma, but this is just because he's been sole caregiver for my grandmother*."

- Thomas [care partner]

It was also a common theme for participants who were caring for someone with dementia to put off taking care of their health. Some were routinely behind in their preventative medical screening.

"*I have to stay here and look after him, and my health is failing, too, right?*

It's, it's starting to affect me, like my health and everything."

-Sophia [care partner for Indigenous spouse]

"*...so I was with him both days, so I didn't look after myself*"

- Irene [care partner for spouse]

The places where care is offered are often limits individuals' ability to make informed, supported choices. Environment and place are very important when considering being well for both people living with dementia as well as care partners. Thomas recounted an advertisement for a car where someone with dementia was being driven around a city to stimulate memories, and he stated, "*That's so similar to things we've been going through with my grandmother*". The environment or location was the factor that was creating connection to being well. This topic is highly related to safety as well.

"*He's sitting outside. And that's what he likes to do.*"

- Sophia [care partner for Indigenous spouse]

"*Because, like, my mom is in a home, and I don't like it. But I work, I can't look after her*."

- Martha [care partner for parent]

Chloe commented on how locked wards for dementia are places where "*You have your bed, you have your bathroom, it's easy to clean stuff.... and puzzles, a couple of the chairs, and maybe there's like one fish tank, 'cause there seems to always be a fish tank*." She went on to clarify:

I understand logistical difficulties that come up of course, but that doesn't mean you can't make it look homey, or have space to maybe personalize, bring your own taste into it - maybe there's decorations everywhere, you know, that are within reason for someone with dementia..."

- Chloe [health care worker and care partner for grandparent]

4.2.2.3 Being Well - Subtheme: Cultural

Meaningful connection to culture was a frequent theme that was generated; however, this connection is specific to the needs of individuals. Assuming every Indigenous person is connected to culture in the same way is detrimental to being well. Zoe, a healthcare worker stated that the importance of culture and beliefs was integral for Indigenous people with dementia that she had supported. Irene alludes to a cultural connection created by an Indigenous seniors' centre, instead of only offering crafts.

"*I do feel like [Indigenous] culture and [Indigenous] beliefs and systems are very integrated and they're not forgotten*."

- Zoe [health care worker]

"*They're very good at cultural things and if you wanted to participate it's not only just crafts and lunches."*

- Irene [care partner for spouse]

Edward's mother had not previously been engaged with Indigenous cultural practices but as her dementia progressed it became integral to her. She also described how meaningful

connection to culture has influenced her contextual understanding of her family and created resilience.

"*[Culture] ended up becoming very important to her. As she was dying it was important to her."*

- Edward [care partner for parents]

"*I reconnected to [cultural practices] as I've gone later in life…It's actually personally helped me understand a lot of where my family comes from and also the things that happened to them that caused them to behave the way they did*."

- Edward [care partner for parents]

Participants described that there were often barriers to being well when trying to meaningfully connect to culture. Martha described the barriers that hindered smudging in her mother's care facility. From our interview it was very clear she was becoming impatient and annoyed at the care facility's inability to provide person-centred care for her mother. When multiple barriers detract from being well culturally this harm is then exacerbated in the theme of cultural safety.

"*One, because smoking is a hazard, and it's a small smoke. Two, it's the smell. People are allergic to smells and get sick at smells. And then three, it'll set off fire alarms and whatever. So yes, we recognize all that, but she's still not allowed to do it. And then C, D, E, F, G, no one wants to take her to do it*."

- Martha [care partner for parent]

4.2.3 Theme 3: Safety

What is safety? The consideration of safety for people living with dementia, their care partners, families, and communities is incredibly important in the context of this framework. Issues of safety can arise in multiple contexts including home-care environments, outdoor environments, and during access to medical services. In some cases, there can be physical or emotional violence that is experienced. Specifically in the context of Indigenous-centred dementia care, cultural safety is an especially important consideration. Table 5 shows the analysis process for the theme of safety and illustrates examples of descriptive codes and corresponding quotes as well as my theoretical interpretations using field notes for context. I present a more detailed description of the analysis and findings after the table.

Table 5: Process of defining safety within three subthemes

Theme 3: SAFETY			
Subtheme	**Descriptive Coding**	**Quotes**	**Field Notes**
Social	social, safety, dignity, relationships, dementia progression	"*Community support is so important, even in the smallest way when people, families are going through this, because that journey needs to stay holistic and healing and learning, instead of what's going now in fear, hiding and then just suffering and dying*" - Lee Marie	•*Social safety is so important* •*What happens to the people who don't have anyone to advocate for them?* (2024-2-8)
Physical	access, dementia progression, physical	*"A primary care facility with people that actually care, not that are just getting a paycheck. You have some supports in the hospitals for Indigenous people, but that person is probably one person run ragged..."* - Nora	•*this is fundamental to dementia care in general* •*assumption that dementia is part of normal aging* (2024-3-6)
Cultural	cultural safety, tradition, healthcare, care facility, residential school	"*We've had cultural barriers with her nurses...she remembers her berry-picking... remembers all these times. And they try to explain to her, but they themselves don't understand, so I just think that it's another hurdle we have to cross*." - Martha	•*entwined with the other themes of relationality and being well* • *the concept has to be integrated with the other themes to be effective* (2024-4-18)

4.2.3.1 Safety - Subtheme: Social

Social situations and relationships should have a high degree of safety. This includes health care workers and the ways that may be adding or detracting to safety, as well as family relationships, community relationships and care partner relationships. Thomas stated that the most important thing to consider for Indigenous-centred care from a health care worker perspective was:

"... having people encourage [cultural] practices and feel safe because with dementia it can start to feel unsafe, and you just don't remember details or oftentimes people feel unsafe. So, I think anything that adds to feeling of safety."

- Zoe [health care worker]

Because dementia is often an isolating and stigmatized condition, Earl stressed the importance of having a social relationship based on advocacy.

"*It's very easy for a patient in long-term care, maybe in other places, but for a senior with dementia and long-term care, it's really, really easy for them to get just kind of brushed aside, and lost in the weeds, they need to have a person that really advocates for them all the time*."

- Earl [care partner for parent]

A common piece of social safety was the balance between remaining at home or moving to a care facility. This is a complicated topic that is dependent not only on social safety, but also physical and cultural safety. Zoe describes the intensity of witnessing the outcomes of this scenario.

"*So, the incentive to go into these places never comes until they lose their ability to make decisions for themselves. Someone else has to be there for them, and it's very hard to witness."*

- Zoe [health care worker]

Edward described his attempt of balancing the accountability of a western schooling institution and his cultural expectation of taking care of his dying mother.

"*Stop using your mother's health as an excuse to not come to class." and things like that, and there was, there was the cultural expectation of me being there… you know, my mother was dying*."

- Edward [care partner for parents]

The difficulty and burden of taking care of loved ones with dementia was mentioned by every participant that was also a care partner. Sophia reflected on the balance of sadness and relief regarding the eventual death of her partner who was experiencing many health declines in the home that were becoming unsafe. Martha knew that moving her mother into a home was the best option, but it was also a source of stress and guilt.

"*Um, it's gonna be hard. I know it. But it's gonna be [a] relief, 'cause he's... I don't know. He's got cancer, too*."

- Sophia [care partner for Indigenous spouse]

"*And this is what I do struggle with, yes. My guilt. That's a big thing. You'll most likely hear it from most of your participants. The guilt alone can kill."*

- Martha [care partner for parent]

4.2.3.2 Safety - Subtheme: Physical

Physical safety considerations occur in in a care facilities, hospitals, or home environments and also involves the ability to access resources and supports. Thomas strongly stated:

"*Yeah, where the facilities are, the system is broken…When you look at the programming - I'm not saying they don't exist. I'm not aware of any Indigenous specific dementia programming focus on support*."

- Thomas [care partner]

Nora shared that there are many contributing factors to the state of dementia in the community that she lives in:

"*There is not enough housing and not enough supports and not enough diagnosis, it's just self-diagnosing, so we don't know."*

- Nora [care partner for aunties]

Zoe and Alice addressed the current state of care facilities available with appropriate care with Indigenous people living with dementia and how they are not adequate.

"*A part that needs to be looked to is that care is culturally sensitive because the homes and stuff that we have right now are not appropriate. Especially with it being institutionalized and that generation of people and the things they've gone through and that they've walked through just having to be in an institution is not comfortable*."

- Zoe [health care worker]

"*With dementia, people enjoy familiarity, and when you're used to living on a reserve and then you're put in a locked unit with, as you would say a bunch of Caucasian people that have a different background it can be very frustrating because nothing, nothing's familiar, there's no religion, the foods different, the people are different*."

- Alice [health care worker]

Institutional trauma from a history of Indian residential schools, Indian day schools and treatment in Indian hospitals was described as a concern from many participants, including Thomas.

"*I can't remember which one it was, but I've heard of a few facilities that had some Indigenous folks in them who had dementia, and it's been a train wreck because it's [brought up] residential school trauma all over again*."

- Thomas [care partner]

4.2.3.3 Safety - Subtheme: Cultural

It was highlighted that the current state of dementia care is inadequate to support Indigenous people, especially in consideration of cultural safety. Accessing cultural supports or being able to engage in cultural practices is very difficult in the current environments. When I asked Zoe what she would advocate for regarding access to a cultural space she said:

"*Like we need a space for patients to go to, and if they could have it be like a circle, and they could do drumming and smudging like if it was vented properly and that kind of thing*"

- Zoe [health care worker]

Alice mentioned how there is not Indigenous-specific programming in long-term care facilities and how there are options for some other religions to engage but not specifically for Indigenous people.

"[Indigenous people] also don't have access in places like senior facilities to cultural um teachings and stuff and normally they would otherwise. A lot of facilitated senior homes are more recreational and there, when it's religion and things like that there's not really anything spiritual offered for [Indigenous people]."

- Alice [health care worker]

Edward disclosed the that many Indigenous people do not feel comfortable asking for accommodations or access to cultural practices, and Zoe and Alice described how many continuing care systems congregate living units require someone to ask and advocate for cultural access like smudging. This indicates that there is a gap in terms of access, and this is compounded by culturally unsafe care and racism.

"*The assumption is there that you're like, "I can't ask for that." So, the assumption is there that you, you don't belong in asking for anything like that. You don't deserve differently, right?"*

- Edward [care partner for parents]

"*You can't really [smudge] in a facility because there's never enough staff to take you outside - 'cause you can't do it inside*."

- Alice [health care worker]

Edward described the importance of connection between non-Indigenous people and Indigenous people and later revealed how beneficial it would have been to have connection to cultural supports when attempting to navigate his mother's experience with dementia when he was in his early twenties.

"*When it comes to navigating any kind of colonial system like healthcare- … or just people not of your culture saying get the hell out of here, there's no real connection there*"

- Edward [care partner for parents]

"*As a caregiver, you're going through a little death yourself. And so, with that little death, having access to cultural practices, or having access to community, having access to resources, those things are the things that save people. Those are the lifelines that help prevent people from going into dark places, from people just saying, 'I give up'.*"

- Edward [care partner for parents]

Chapter Four Summary

This chapter has described the important themes of a framework for the development of an Indigenous-centred dementia care approach. Chapter 5 presents a discussion of this framework as well as conclusions and suggestions for future research.

5.0 DISCUSSION

I have described the research questions of this project which include gaining an understanding of the experiences of dementia with Indigenous people living with dementia, their care partners, families, and communities and determining the foundational principles of culturally safe approaches to Indigenous-centred dementia care. To address the research questions, I have presented a framework that encompasses three major themes of Indigenous-centred dementia care: relationality, being well, and safety. I have illustrated that these themes exist within physical, cultural and social contexts.

In this chapter I will discuss how the findings align with the aims of the project. I will also interpret and analyze the findings within the context of Indigenous-centred dementia care and will describe the ways in which the Indigenous-centred dementia care framework contributes new knowledge to the current evidence base of best practices in dementia care. I will also discuss the importance of integrating the Indigenous-centred dementia care framework into current dementia care and interventions with Indigenous people living with dementia, their families, their care partners, and their communities to address the lack of culturally safe care that currently exists.

5.1 Key Findings

The formation of the Indigenous-centred dementia care framework has been guided by and grounded in Indigenous voices and experiences and led by the articles of UNDRIP (United Nations General Assembly, 2007) and the Truth and Reconciliation Commission of Canada Calls to Action (Truth and Reconciliation Commission of Canada, 2015). The framework is centred on the foundational principles of culturally safe approaches to Indigenous-centred dementia care and includes the themes relationality, being well, and safety, and these themes include social, physical, and cultural subthemes.

Integrating an Indigenous-centred dementia care framework into a western system requires understanding the framework I have described in relation to ethical space (Ermine, 2006). Western monoculture and colonialism have perpetuated harm against Indigenous Peoples and have resulted in adverse outcomes throughout post-contact history in all areas of life for Indigenous people. This included the forced engagement and assimilation of Indigenous Peoples into western society through government control. This fact is important to consider when examining the ways that person-centred care has been 'western-washed' with ideals of individualism and what person-centred care looks like, or who exactly the 'person' is that this care has being designed for. The western understanding has been considered as the norm throughout post-contact history, but in order to move towards reconciliation these systems have to change and adapt. As a non-Indigenous person working with Indigenous people, I have tried to uphold the responsibilities and significance of ethical space. Through this, I have attempted to map

methods of person-centred care with approaches to Indigenous-centred dementia care. Being led by Indigenous communities we co-created critical facets of Indigenous-centred dementia care through partnerships. By listening to the people who took part in this study, and aligning to the calls to action outlined in chapter 2, a solutions-based discussion is presented here to bridge the gaps of dementia care experienced by Indigenous people.

Wilson states that "*relationships do not merely shape reality, they are reality*" (Wilson, 2008, p. 7). With this in mind, the importance of relationality in the context of dementia care with Indigenous Peoples cannot be understated. Most of the participants I spoke with situated themselves in terms of their place in their family order, and all of them described pieces of importance regarding their relationships with others. Tynan (2021) articulated that relationality includes the responsibilities individuals have to one another, and this was extremely evident in how participants described their relationships in this study.

5.1.1 Care Partner Experiences

Being a care partner can be extremely challenging and is a demanding role (Gubhaju et al., 2022). Westrelin et al. (2024) found that for spouses in particular, the shift back and forth from care partner back to spouse can be complicated, and that spouses often search for personhood with the person living with dementia. This study found that the search for personhood is a key feature of the experience of care partners and family members. For

Irene, the fluctuation in Walter's cognition and memory were confusing for both her and Walter because one day he would remember something, and the next day he wouldn't. However, she resolved to hold onto the core person he is despite the cognitive fluctuations. Similarly for Earl, the reminders of love that she held onto from when she was young connected her to her father's personhood.

Care partners have a high risk for negative health outcomes from the additional stress of the experience of caring for someone living with dementia (Richardson et al., 2013). Care partner participants in this study described how they felt that their health often took lower priority than the health of the person living with dementia. Chloe shared her belief that many care partners end up passing away from the stress and burden of caregiving before their loved ones. This self-sacrifice and the accompanying exhaustion were frequently reported and difficult to hear from multiple participants. Relationship changes in the context of dementia can also exacerbate mental health issues such as loneliness due to experiences of stigma as well as social exclusion for both care partners and people living with dementia (Kotwal et al., 2024). Snyder et al. (2015) discussed secondary stressors such as financial insecurity and lack of access to resources. Participants in this study who were involved as care partners often described a lack of access to resources or expressed a lack of awareness of the services available, which led them to feeling isolated. Huizenga et al. (2023) found that for people living with dementia, everyday life is about managing a constant balance. Although this was not found for participants living with dementia, this was reported by care partners in this study. Many individuals described difficulty in the mounting tasks that piled up when trying to juggle

ordinary life tasks on top of being a care partner with someone living with dementia. Participants often relied heavily on neighbors and friends for support for tasks such as mowing the lawn or snow removal. Relying on neighbors for help was also found with people living with dementia by Odzakovic et al. (2021), and the current study adds that this is also important for care partners.

There is also a reported lack of available resources for family members who have to navigate the healthcare system and biomedical aspects of dementia alone, and sometimes as a younger person. As Indigenous people are more often diagnosed with dementia at younger ages than non-Indigenous people (Jacklin & Walker, 2020), the responsibility of care can frequently fall to younger care partners. Younger care partners will inevitably need support and resources for navigating the increased challenges of being a care partner and having someone depend on them. Participants noted how they wished there was some kind of instruction book for decision-making support such as navigating personal directives, estate planning, and how to access financial resources. Although there is an increasing amount of grey literature available for this information (Alzheimer Society of Canada, 2022, 2024b, 2024c), much of the information is designed for older adults living with dementia and their care partners, and most of the information provided is not Indigenous specific.

Dealing with stress from the role as care partner is important because high stress may have long term health impacts (Snyder et al., 2015). Participants in this study mentioned several ways of coping with stress. Sophia used humor with Arthur to cope, as

well as making time to work on sewing projects. Nora described that her auntie Sylvia's experience with dementia showed her how having an executive plan in place in the event that she develops dementia was a way to cope. Having a connection with family, neighbours, and friends was deemed as important in coping with experiences around dementia. Odzakovic et al. (2021) stated that building meaningful relationships with neighbors and community can take a long time to establish, so there is importance in supporting existing relationships (Odzakovic et al., 2021). This point is important to consider in relation to people living with dementia remaining amongst community. Quality of life for people living with dementia is positively impacted by maintaining connection to a neighborhood and community (Odzakovic et al., 2021; Wiles, 2005). Unfortunately, the displacement of someone from their local community is a frequent occurrence for Indigenous people accessing health care services (Hayman et al., 2009; Monchalin et al., 2020).

5.1.2 Health Systems

The onus must be placed on the health care systems and providers to provide person-centred care and culturally safe spaces (Webkamigad et al., 2020; Whyte et al., 2024). As specifically shared by Zoe, the lack of access to culturally-safe care facilities has led to a lack of informed decision-making options for families. This led to poor health outcomes for either keeping a family member in a home where their care may be unsafe because of the lack of resources or lack of care by family members. Often, the only

alternative option is to move the person living with dementia to a care facility that may not necessarily be culturally safe and can be geographically distant from their current home and/or family. Many participants mentioned the lack of options regarding culturally safe senior's care facilities. They described that moving the family member from their home, away from their community into an isolated, western institution-based care facility was often the only choice. For Nora's auntie, Sylvia, the first available home (not an Indigenous-specific care facility) was 485 km away from where her family lived, which would have been a 5.5-hour drive. The Canadian government has a long history of active harm through colonial practices under the illusion of improving Indigenous Peoples' health. This includes Indian hospitals for tuberculosis that resulted in mass deaths and forced clinical research (Granzow, 2021; Komarnisky et al., 2016; Lux, 2016; Mant et al., 2023) as well as the formation of residential schools which have resulted in multigenerational trauma and negatively impacts the health of Indigenous s oday (Truth and Reconciliation Commission of Canada, 2016). Almost all participants from this study mentioned aspects of the harms and outcomes of institutionalization, residential schools, and racism, which is frequently also consistently mentioned in the literature (Oster et al., 2014; Paradies, 2016). Thomas specifically recognized the lack of safety in how long-term care facilities echo the design of institutionalized spaces. The structural and procedural design of western medical facilities are fundamentally unsafe for Indigenous people living with dementia. Participants described that access to participate in cultural or traditional activities such as smudging is hindered in units because individuals have to ask staff for permission. This is also present

in care facilities where staff may be required to accompany an Indigenous person outside to smudge.

The literature also supports that health care workers need to recognize the impacts and consequences of residential schools on the health of Indigenous Peoples and the ways they are complicit in care that may be unsafe for Indigenous People (Forbes et al., 2013). As reported by Crawford (2019) in the National Post, during an outreach visit to the Ottawa Hospital in 2019, Brooke Stratton was told by staff that if she wanted to assist a client to smudge it could possibly be accommodated in the Emergency Department. The Emergency Department staff then told Stratton that smudging could only be done in the hospital chapel because that is where people go to heal. Due to the longstanding harmful interference of the church in the lives of Indigenous people, she refused. She eventually resorted to taking her client to smudge outside in -19C weather. Although the Ottawa hospital has a lengthy manual on accommodating cultural practices, "*smudging in a patient's room is only allowed if the other options aren't available, or if the patient is near the end of life*."(Crawford, 2019, p. A7). This clearly demonstrates that cultural safety protocols are not enough to affect meaningful change in health systems.

5.1.3 Person-centred Care vs Indigenous-centred Care

The concept of person-centred care involved a shift towards understanding that dementia is a subjective condition that changes depending on both individuals and

context. This also signified a move away from medical and behavioural dementia treatment, and involved a more holistic, human approach instead of simply treating a condition (Fazio et al., 2018; Kitwood, 1997). This sentiment was echoed by the participants in this study. The most touching stories shared with me were from the perspectives of care partners who were fierce advocates for the people in their lives living with dementia. So much of what they were defending was the importance of dignity and personhood. Simple things such as a healthcare worker getting to know a person well enough that they use an old nickname with them, and they talk with them about past experiences that were meaningful instead of just doing basic medicalized care. This level of care can also enhance the preservation of dignity. Schou-Juul et al. (2024, p. 6) stated that "*nurturing the social care of people with dementia and preventing their loneliness plays a role in upholding such basic dignity*". They also described that although professionals differed in their definition of dignity, there seemed to be a foundational understanding that dignity should be maintained for patients despite cognitive differences (Schou-Juul et al., 2024). Hobson et al. (2019) outlines aspects that threaten the dignity of someone living with dementia such as treachery, disempowerment, objectification and infantilisation and specifies that enhancing dignity can include celebration, negotiation, recognition and validation.

Person-centred care relies on authentic contact and communication as well as empathy and individual observation. Kitwood (1997) described that a failure to recognize and affirm personhood and individuality will have consequences. He also describes that maintaining a 'way of life' and personhood is integral to person centred care. He also

describes the notion that individual attention, meaningful activities, personal support, and involvement in decision making are also integral to person-centred care. The importance of meaningful activities has also been described by (Allison et al., 2022).

The results from this study show that relationality in the context of dementia is central to the provision of quality care. Participants alluded to a lack of person-centred care often alongside a loss of personhood which is integral to maintaining dignity and identity and integrity as noted by Kitwood (1997) . This is an example of the concept of embodied relationality, which has also been described (Kitwood, 1997). The foundational ideas of person-centred care coherently map across the framework of Indigenous-centred care to be joined in ethical space. There is an emphasis placed on the importance of the interconnection between biological, psychological, and social factors that surround a person living with dementia and this care is heavily reliant on communication and relationships (Kitwood, 1997). Nolan et al. (2006) present the Senses Framework that describes six 'senses' that constitute a framework to promote quality care for older people and to move toward more humanistic care. The senses include security, continuity, belonging, purpose, fulfilment, and significance. They describe that person-centred care cannot focus solely on the individual, because every individual exists within a network of relationships. In other words, relationality needs to be at the forefront of care so that important meaning is co-created by patients, family members, care partners, and community members, and thus more significant (Nolan et al., 2006).

While person-centred (Kitwood, 1997) and relationship-centred (Beach & Inui, 2006) research, and frameworks like the Senses Framework (Nolan et al., 2004) are approaches that are foundational to understanding the components of high-quality dementia care, these concepts remain developed in a western paradigm and still do not meet the specific needs of Indigenous people living with dementia. It is important to understand that 'health' or being well as it was described in this study, is a multidimensional and holistic concept (Tsuji et al., 2023; Yap & Yu, 2016). Indigenous ways of defining and describing being well can differ greatly between western ways (Tsuji et al., 2023). Western ways of defining being well and living well have been described in terms of social capital, resources, and assets (Clare et al., 2019). Indigenous ways of defining health are more related to the interconnection of physical, mental, spiritual and emotional health not only for an individual but for their community (Butler et al., 2019; Griffiths et al., 2022; Molyneaux & O'Donnell, 2009; Tsuji et al., 2023). In other health settings this has involved a meaningful connection to culture and language (Oster et al., 2014). It is important to note that desire for connection to Indigenous culture and the intensity of that connection can vary between individuals (Whyte et al., 2024) and a one size fits all approach is often ineffective. Participants in this study had varying connections to their own individual Indigenous cultures but made special mention of the importance of recognizing the aspects of individual identity and culture and incorporating that into dementia care. Being well is also not a metric that once achieved, is solved. It is a constant flux of being, and impacted by many factors such as an individual's cognitive decline,

changes in social network and support, as well as changes in care partner responsibilities and stress (Kotwal et al., 2024).

In a study that took place in southwest western Australia, participants described that the lack of awareness of dementia they perceived in their own communities may be due to feelings of stigma or shame from knowing or being a person living with dementia (Gubhaju et al., 2022). Nora spoke about how she didn't realize that dementia was prominent in her community until her auntie Sylvia was diagnosed with dementia, and that her other family members were judgemental toward Sylvia. Previously, she assumed the memory loss and exit-seeking was a normal part of getting older and stated that a lot of people she knows end up relying on 'self-diagnosing' their family member with dementia due to the lack of services, especially within communities or on reserve. There is clearly a need for increased awareness and education for recognizing symptoms of dementia in ways that are meaningful and appropriate for specific communities (Gubhaju et al., 2022). To bridge gaps in health literacy in Indigenous communities in Canada, a collaborative project between researchers, Health Canada's First Nations and Inuit Home and Community Care Program, and Elders resulted in a framework for health promotion materials that were culturally grounded (Webkamigad et al., 2020).

For cognitive assessment specifically, LoGiudice et al. (2006) developed a cognitive assessment tool for Indigenous Australians which showed promise for adaptation to local contexts. It has since been validated with Torres Strait Islander Peoples (Russell et al.,

2024), as well as Anishinaabe communities on Manitoulin Island in Canada (Walker et al., 2021).

5.1.4 Indigenous Safety Within Dementia Care

A reported barrier related to cultural safety by the participants in this study was the lack of recognition of the importance of Indigenous culture when accessing dementia care services. Webkamigad et al. (2020) has described the importance of cross-cultural communication in health systems. Health care facilities are frequently staffed with people from a multitude of cultural backgrounds and ethnicities (Debesay et al., 2022; Lightman, 2022) and this can lead to barriers in effective communication and care if Indigenous culture is not also recognized. This was described by Martha who was understandably frustrated by health care workers who didn't recognize her mother's Indigenous spiritual beliefs. Webkamigad et al. (2020) suggest that the consideration of communication strategies such as non-verbal interactions, increased compassion, and humour can increase relationality and meaningful relationships. Truswell et al. (2019) explains that the notion of spirituality is complex due to multiple cultural understandings, however, he states that acknowledging an individuals' cultural framework and developing a deeper understanding can lead to improved relationships. He also states that by respecting individuality and social inclusion of people living with dementia "*spirituality has the potential to provide an anchor to individual identity and also to offer a supporting route to personal development*."(Truswell et al., 2019, p. 116).

Solutions for health care barriers with Indigenous People must involve solutions that are developed with specific communities or that can be adapted to specific communities (Forbes et al., 2013). The results from this study show that there is a need for Indigenous-specific, culturally safe supports and interventions that are designed for both the person living with dementia as well as care partners, families, and community members. This need has been echoed by other studies on Indigenous experiences of dementia. Gubhaju et al. (2022) found that community awareness of dementia needs to be improved through culturally relevant education and by ensuring health care workers are providing culturally safe care. Similarly, Cox et al. (2019) describes the need for community-based dementia education, and the provision of culturally safe dementia care services. The experience of Indigenous People living with dementia can be deeply related to 'place' and cultural spaces. Pace (2020) suggests the connection to place could be recognized by developing culturally safe programs in local contexts, reducing social isolation by preserving geographic proximity of housing (Pace, 2020), and nurturing intergenerational teaching (Cornect-Benoit et al., 2020; Pace, 2020).

Yamane and Helm (2022, p. 167) state that in order to move towards health and wellbeing, the design of health promotion interventions need to shift towards a Culture-as-Health approach. They suggest that these "*practices contribute to self-determination, sovereignty, and liberation*"(Yamane & Helm, 2022, p. 167). This definition encapsulates the interconnection of the Indigenous-centred dementia framework presented in this study. It was challenging to isolate each individual theme and subtheme because of the interconnected nature of Indigenous experiences of dementia and Indigenous worldviews.

Further analysis and reflection made me realize that this is, in fact, the strength of this framework. The Indigenous centred dementia care framework fills the gap because it shows the connection between the themes and subthemes and illustrates how bringing person-centred care and Indigenous-centred care creates ethical space for the betterment of Indigenous people living with dementia, their families, and their communities.

5.2 Conclusions

So far, this chapter has situated the findings of the study in the broader context of Indigenous dementia care, and described how the Indigenous-centred dementia care framework can function as an aspect of ethical space that tailors person-centred care to an Indigenous-specific framework.

5.2.1 Pathways to Impact

Dementia prevalence among Indigenous populations urgently needs to be addressed, as does the lack of published information related to Indigenous Peoples experiences of dementia care. This study also highlights the gap in knowledge of healthcare providers on the availability of community resources to support dementia care and suggests that western understandings of dementia are largely based on medical aspects of health as opposed to social aspects. The health-related Calls to Action outlined

by the Truth and Reconciliation Commission of Canada (Truth and Reconciliation Commission of Canada, 2015) can be used to guide appropriate action on addressing dementia to improve care available and appropriate for Indigenous people. Understanding the experiences of dementia from Indigenous perspectives and ensuring that culturally safe dementia interventions are accessible for Indigenous populations in Canada will help to close the disparities in health outcomes between Indigenous and non-Indigenous people living in Canada.

5.2.2 Study Limitations and Future Research Directions

This study had a number of limitations. The gender ratio was nine women to three men; therefore Indigenous male perspectives may not be thoroughly represented in this study. The Indigenous identity of participants was mostly Métis individuals which will not necessarily be representative of all Indigenous experiences; however, the Indigenous-centred dementia care framework should be adaptable to local contexts. Future research should aim to include more Indigenous males and purposively recruit such individuals. It would also be wise for future work to be undertaken in ethical, relational ways with other Indigenous communities and Nations to understand if the framework developed here is applicable in other contexts. By examining the interconnectedness of relationality, being well, and safety, future research should focus on the creation an Indigenous-centred dementia intervention that specifically targets aspects of care that Indigenous people have outlined and placed importance on through participation in this study.

5.2.3 My Future Directions

Being invited into this space as a non-Indigenous person has not only made me a better researcher but has also made me a better human. I am eternally grateful to the people who shared their stories with me, and I look forward to continuing to engage and learn in this space throughout my career to maintain my relationships and reciprocity to the work and to the people I work with.

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Appendix

Appendix A: Recruitment Poster

Appendix B: Recruitment Email

Dear [Potential Participant Name],

I'm contacting you because I, along with the rest of my research team from the Cumming School of Medicine at the University of Calgary, are conducting a research study. The purpose of this research study is to develop and pilot a culturally safe Indigenous-centred dementia care approach that integrates proven person-centred approaches and structures with Indigenous-led components. This will provide information for Indigenous community-based research that bridges the divide between research and community and sees that the that the knowledge gained is directed by and useful for Indigenous communities.

You were identified as a possible participant in this study because you are an Indigenous person who has dementia, you are a family members or caregivers of an Indigenous person living with dementia, or you are a community member with other experience of dementia. It is expected that approximately 15-20 participants will be recruited through Indigenous communities and organizations.

Your participation in this research study is voluntary. I have attached the information sheet/consent form just for additional information for you to consider this request.

If you choose to be in this study, you will be asked to participate in a one-on-one interview with a research assistant over the telephone or video conferencing. We expect that these interviews will take a total of about 30 to 60 minutes of your time.

Please contact me via email reply or at [redacted] if you have any questions or would like to discuss this in more detail. This study has been approved by the Conjoint Health Research Ethics Board: ethics number REB22-1413.

Appendix C: Informed Consent

UNIVERSITY OF CALGARY
CONSENT TO PARTICIPATE IN RESEARCH

TITLE: **Innovation for Indigenous-led Dementia Care to Enhance Safety (VOICES)**

SPONSOR: University of Calgary

FUNDER: **Canadian Institutes of Health Research (CIHR)**

INVESTIGATORS:
Primary Investigator:

Dr. Pamela Roach
Telephone: (403) 210-7574
Email: pamela.roach@ucalgary.ca

Co-Investigators: Lynden Crowshoe, Jennifer Walker, Rita Henderson, Lisa Bourque Bearskin, David Hogan, Jayna Holroyd-Leduc, Dallas Seitz, Zahra Goodarzi, Jeffrey Proulx, Vivian Ewa, Richard Oster

INTRODUCTION

Dr. Pamela Roach and associates from the University of Calgary, McMaster University, Thompson Rivers University, Brown University and Indigenous community members are conducting a research study.

This consent form is only part of the process of informed consent for your participation in the focus group. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you are an Indigenous person living with dementia, a family member/caregiver of an Indigenous person living with dementia, or an Indigenous community member who has experience with dementia. Your participation in this research study is voluntary.

WHY IS THIS STUDY BEING DONE?

The purpose of this research study is to develop and pilot a culturally safe Indigenous-centred dementia care approach. This approach will integrate proven person-centred approaches and structures with Indigenous-led components. This will provide information for Indigenous community-based research that bridges the divide between research and community and sees that the that the knowledge gained is directed by and useful for Indigenous communities.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

In total, we anticipate 50 participants in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study:

- You will be asked to confirm your availability to participate in an interview. This will be arranged through email communications. Your participation will either be in person, online through secure videoconferencing, or telephone.
- Interviews will be recorded and transcribed using Rev.com (Rev.com is a transcription service that has been reviewed by IT and can be used for research purposes. Rev has a strict confidentiality policy, and your files are private and protected from unauthorized access).
- Each interview will take approximately 1 hour of your time.
- After your participation, you will be compensated for your time.

HOW LONG WILL I BE IN THIS STUDY?

Interviews will last approximately 1 hour.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

There are no significant risks to participating in the study. You may experience discomfort with the possibility of discussing, or being reminded of, emotional or traumatic experiences. What you share during the interview is up to you and the study team will not ask you to discuss anything that you do not wish to talk about. If you do experience psychological impacts, we can refer you to mental health resources.

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

There will be no direct benefit to you from participating in this study. However, as someone living with dementia or a family member or caregiver of someone living with dementia, you may feel satisfied with the opportunity to provide feedback that will be used to develop an understanding of Indigenous-centred dementia care. This study may also help the researchers learn more about the needs of Indigenous people living with dementia, as well as the needs of their family members and caregivers.

WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. Your decision will not affect the standard medical care you receive.

CAN I STOP BEING IN THE STUDY?

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

WITHDRAWAL OF STUDY DATA

You may request that your data be withdrawn for up to 2 weeks after the interview. Please note, although on request data may be withdrawn from the study analyses, the raw data must be kept for the minimum required data retention time of 7 years after the closure of the project, as required by the University of Calgary. At this time the raw data will be destroyed.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will be reimbursed for your time. After your participation, you will receive an e-transfer of $100 for your participation. In the event that University of Calgary policies change and e-transfers are no longer available, you will be able to select a $100 gift card from the store of your choosing.

WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible, but there is always the potential for an unintended breach of privacy. The research team will handle data according to the Data Management Plan as outlined below:

- Identifiable information about you will be replaced with a code. A master list linking the code and your identifiable information will be kept separate from the research data.
- Research data and records will be stored electronically on a secure network, operated by the University of Calgary with encryption and password protection.
- Rev.com is a transcription service that has been reviewed by IT and can be used for research purposes. Rev has a strict confidentiality policy and your files are private and protected from unauthorized access.

The study investigators will make every effort to maintain the confidentiality of your research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

All records will be kept in a secure, locked, online database and only research staff will have access to the records. Participants will be identified only by means of a coded number specific to each participant. All computerized databases will identify participants by numeric codes only and will be password protected. Data and study documents at all sites will be stored securely for 7 years, after which they will be destroyed in keeping with the privacy and confidentiality

regulations and guidelines. During those 7 years, the data will be used for presentations, publications, and material for applicable use in clinical settings.

Any future use of this research data is required to undergo review by a Research Ethics Board.

RESEARCHER CONFLICTS OF INTERESTS

There are no conflicts of interest to report.

USE OF DATA FOR FUTURE RESEARCH

De-identified data may be retained for future use. It is your choice whether or not to let researchers share your data for research in the future. If you say "yes," you can change your mind later, but your data might still be used if they have already been shared.

My de-identified research data may be kept for use in future research to learn about, prevent or treat other health-related problems.

❑ YES

❑ NO

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

❑ YES

❑ NO

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

A. The Research Team:
You may contact Lisa Zaretsky at lisa.zaretsky@ucalgary.ca or Meagan Ody at meagan.ody@ucalgary.ca with any questions or concerns about the research or your participation in this study.

B. Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Any results from this study will be published in a confidential manner. Your name or any other identifying information will not be used in any summary or publication. If you are interested in obtaining the results/publication of this study, you should contact the study team.

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- If you decide to take part, you may leave the study at any time.

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

_____
Name of Participant

_____ _____
Signature of Participant Date

SIGNATURE OF PERSON OBTAINING CONSENT

_____ _____
Name of Person Obtaining Consent Contact Number

_____ _____
Signature of Person Obtaining Consent Date

A signed copy of this consent form has been given to you to keep for your records and reference.

Appendix D: Oral Consent

UNIVERSITY OF CALGARY
ORAL CONSENT TO PARTICIPATE
IN RESEARCH

Good morning/afternoon/evening. I'm [name], a researcher with the University of Calgary. You were identified as a possible participant in this study because you are an Indigenous person with dementia, a family member or caregiver of an Indigenous person with dementia, or an Indigenous community member with other experience with dementia. The purpose of this research study is to develop and pilot a culturally safe Indigenous-centred dementia care approach that integrates proven person-centred approaches and structures with Indigenous-led components.

If you choose to take part in this study,

·You will be asked to confirm your availability to participate in an interview. This will be arranged through email communications. Your participation will either be in person, online through secure videoconferencing, or telephone.

·Interviews will be recorded and transcribed using Rev.com (Rev.com is a transcription service that has been reviewed by IT and can be used for research purposes. Rev has a strict confidentiality policy and your files are private and protected from unauthorized access).

·Your interview will take approximately 1 hour of your time.

·After your participation, you will be compensated for your time.

We do not anticipate any risks or discomforts for you if you choose to participate, but depending on what you choose to talk about, sometimes it can be upsetting to talk about negative experiences.

There may be no direct benefit to you from participating in this study. However, this study may also help the researchers learn more about the needs of Indigenous people living with dementia, as well as the needs of their family members and caregivers.

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no consequences to you. Your decision will not affect your care or rights in any way. You can decide to stop at any time during the interview. Please tell the research assistant if you are thinking about stopping or would like to stop.

You may request that your data be withdrawn for up to 2 weeks after the interview. Please note that although on request data may be withdrawn from the study analyses, the raw data must be kept for the minimum required data retention time of 7 years after the closure of the project, as required by the University of Calgary. At this time the raw datawill be destroyed.

You will receive a $100 honorarium for taking part. The $100 will be e-transferred to you. In the event that University of Calgary's policies change and e-transfers are no longer available, you will be able to pick a $100 gift card for the store of your choosing.

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible, but there is always the potential for an unintended breach of privacy. The research team will handle data according to the Data Management Plan as outlined below:

· Identifiable information about you will be replaced with a code. A master list linking the code and your identifiable information will be kept separate from the research data.
· Research data and records will be stored electronically on a secure network, operated by the University of Calgary with encryption and password protection.
· Rev.com is a transcription service that has been reviewed by IT and can be used for research purposes. Rev has a strict confidentiality policy and your files are private and protected from unauthorized access.

The study investigators will make every effort to maintain the confidentiality of your research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

All records will be kept in a secure, locked, online database and only research staff will have access to the records. Participants will be identified only by means of a coded number specific to each participant. All computerized databases will identify participants by numeric codes only and will be password protected. Data and study documents at all sites will be stored securely for 7 years, after which they will be destroyed in keeping with the privacy and confidentiality regulations and guidelines. During those 7 years, the data will be used for presentations, publications, and material for applicable use in clinical settings.

Audio recordings of interviews will be destroyed once transcribed. There are no plans to destroy anonymized data. Data collected for this study may be shared with other researchers for future studies that are unknown at this time. Any data shared with other researchers will not include your name or other personally identifying information.

Any future use of this research data is required to undergo review by a Research Ethics Board. De-identified data may be retained for future use. Along with this, University of Calgary researchers may contact you to ask if you would like to take part in future research.

If you have any questions you can contact:

The Research Team: You may contact Lisa Zaretsky at lisa.zaretsky@ucalgary.ca with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB): If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, the Universityof Calgary at 403-220-7990.

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no consequences to you.

- You have a right to have all of your questions answered before deciding whether to take part
- If you decide to take part, you may leave the study at any time

In no way does your agreement to take part in this study waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

Do you have any questions or would like any additional details? [Answer questions.]

Do you agree to participate in this study?

[If yes, begin the study.]

[If no, thank the participant for his/her time.]

Do you agree to be contacted for future research?

Do you agree to have your de-identified data used for future research?

Appendix E: Interview Guide

Interview Guide
*** The interview guide will be finalized with the support and direction of the project reference group. Below are some examples of the types of questions we anticipate asking in the interviews; however, the research team will submit a modification once the reference group has finalized the guide.**

1. What is your experience with dementia?

2. What does “dementia” mean to you?

3. What are your experiences in accessing cultural supports for dementia?
    - positive experiences?
    - negative experiences?

4. What kinds of things are important to you if you have dementia, or if you have a friend or relative with dementia?

5. How could dementia support services better support you on your journey?
    - What do you want to see?
    - How could things be improved?

6. Is there anything else you would like to add? Anything of importance for you we forgot to talk about? Is there anything else you think I need to know about?

7. Do you have any questions for me?