FILLING IN THE GAP – INDIGENOUS CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA IN 21st CENTURY CANADA: A LITERATURE REVIEW

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Abstract

Dementia is a neurodegenerative medical disorder of adulthood that causes a deterioration of memory and interferes with the ability to perform activities of daily living. Although many causes of dementia are not modifiable, Indigenous peoples are likely subject to modifiable risk factors, and many social determinants of health (like culture, racism and ableism) that could impact their risk of developing dementia (Alzheimer Society of Canada, 2024). Indigenous people (First Nations, Inuit, and Métis) living with dementia and their caregivers within the geographical regions of Canada face challenges that are similar to those of non-Indigenous Canadians. However, they also have unique challenges that can be examined using a Critical Disability Studies framework, which include a review of the intersections of dementia (disability), identity, culture, and systemic barriers in dementia caregiving.

Thereafter, Decolonizing Theory can be used to analyze the intersections of dementia, caregiving for people who live with dementia and Indigenous identity to understand the different coping mechanisms that help Indigenous people living with dementia and their caregivers manage stress. Just as Critical Disability Studies aim to combat the marginalization and stigmatization of people with disabilities, Decolonization can oppose the ableist beliefs that colonial processes have ingrained (Roy, 2024). Furthermore, understanding how colonialism, marginalization and systemic inequities create stress for Indigenous people living with dementia and their caregivers can be achieved through Postcolonial Theory. Postcolonial Theory provides the basis for much cultural safety training and is an explanatory framework for Canadian healthcare

providers practicing with Indigenous peoples. It proposes that providing healthcare to Indigenous peoples requires an understanding of the postcolonial relationship between Indigenous peoples and the Canadian settlers (Wilmot, 2021). The framework of Two-Eyed Seeing or *Etuaptmumk*, can then explain how there are many ways of understanding the healthcare world, including the Western biomedical model, and the various knowledge systems used by Indigenous peoples in the development of caregiving support models.

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Prologue

For many reasons, I had not considered attending university. The door to postsecondary education appeared closed as I lacked the required high school courses. However, a lack of meaningful employment and my love of reading classic literature prompted me to apply to McMaster University as a mature student. I have been fortunate that my mother (Mom) followed a non-traditional educational path into McMaster Medical School. She believed that my passion would someday also reveal itself. Enjoying interdisciplinary Humanities courses, I explored Classical Studies through language (Latin), literature, ancient art and music, history, and psychology until I found my academic home in anthropology/archeology. Through that program, I participated in two archaeology field schools – the first was in Dundas (2018), where I excavated Indigenous artifacts under Indigenous supervision, and the second was in Gravina, Italy (2019), where I excavated a 2nd-century Roman gravesite. During that time, I wrote an anthropology paper about heritage protection, "Indigenous Communities and Canadian Archaeology: Denial or Protection of Heritage?" Most importantly, I learned that research about (and with) Indigenous peoples should not be proposed or undertaken without their participation from conception to completion. The concept of allyship became an essential factor in considering graduate school programs that could support my interest in Indigenous health issues.

It was not only educational experiences that deepened my passion for Indigenous culture, learning about colonization, agency, racism and "othering." After reading my 'Heritage' paper, Mom encouraged me to attend an Indigenous Health conference to

explore educational and employment options. I learned about environmental health, climate change, water insecurity, and social determinants of health. My Mom's friend and colleague, Dr. Amy Montour, spoke of 'Two-Eyed Seeing" that has come to embody my journey. Dr. Montour said, "When you are using that Two-Eyed Seeing, whether you are Indigenous or non-Indigenous, it requires you to spend a lot of time and self-reflection on engagement and relationships… Build a community for yourself; you will need multiple perspectives and ideas to guide you along the way." Learning about traditional healing and ways of knowing, I realized I had long been exposed to these concepts.

In New Brunswick, my mother explored her Acadian and Mi'kmaq ancestry for years. There is evidence establishing our Indigenous ancestry through three grandmothers (born between 1650 and 1850), but our family does not claim Indigenous (or Métis) status. After moving to Ontario, we met a traditional Mohawk teacher and healer from the Six Nations of the Grand River Territory, who welcomed us into many Indigenous ceremonies. As a child with disability (cerebral palsy and epilepsy), I benefited from ceremonies and traditional medicines, alongside Western medicine.

Since the *Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls* (2019) was published, discussions about my Indigenous grandmothers have changed. Once excited about our ancestry, my mother and I wondered if our Indigenous grandmothers might not have married the French grandfathers for love. One of my grandmothers was stripped of her identity, and the proof is a marriage certificate that only listed her as "Marie, une Indienne." The second was a daughter of Madockawando, a Penobscot chief. In 1685, Mathilde Nicosquoue married Jean-Vincent

d'Abbadie de Saint-Castin, a French military officer during King Louis XIV's War of the League of Augsburg, also known as King Philip's War. Although he later became an Abenaki chief, we wondered if the reports of polygamy with another of Madockawando's daughters might not have reflected a sexually inappropriate story.

I am not sure how I came to be fascinated with the topic of my MRP. My first memories of meeting someone with dementia were when I spent my early high school summers at St. Joseph's Villa LTC. Unable to find paid employment, my parents insisted I volunteer my time somewhere. Mostly, I ferried residents between their rooms to participate in recreation programs or play games. I was shy and had no previous experience with people who had dementia. I cannot remember whether their inability to recall conversations from even minutes before was amusing or annoying. However, as a surly teenager, I recall not enjoying the experience very much.

Nevertheless, living in a doctor's house, I was exposed to many stories because Mom, if nothing else, is a storyteller. Over the years, Mom has worked in hospitals and an LTC facility and has become a Palliative Care specialist. Most of her patients were old and dying. In recent years, there were stories of people who chose to have Medical Assistance in Dying. Although I could not pursue a career in medicine, I remained interested in the field of healthcare. Therefore, it is not surprising that the subjects of my graduate papers were related to healthcare. Nor is it a surprise that I found a way to explore healthcare issues for Indigenous peoples during my graduate program.

In the first year of the CDS program, I had the opportunity to explore various aspects of dementia and caregiving through literature reviews. In Mental Health Policy, I

analyzed existing federal policies to propose a new framework to guide the development of "National Guidelines to Support Caregivers of Adults with Dementia." In Disability Law, I provided research opinions about why Medical Assistance in Dying for Canadians with Dementia is problematic. However, these papers did not give any Indigenous perspectives. It was not until my first meeting with Dr. Hillier and Dr. Vorstermans that I began to solidify my MRP topic. I was tasked with writing about a gap in the research, and I was encouraged to write about something that I could enthusiastically devote the next two years of my life to.

After a long recovery from COVID-19 (in 2022), I decided to move to Ottawa. I had hoped to one day work for the Public Service, but I soon became disillusioned, learning that the hiring programs offered to those with disability were more lip service than reality. I applied widely to entry-level policy and program jobs in Indigenous Affairs, learning about programs such as Jordan's Principle and Indigenous Archives. Developing an interest in the intersection of research and policy, I applied to, but was not accepted into, the Indigenous Policy and Administration Program at Carleton. Finally, in 2024, I secured a Student Research Assistant position at the Bruyère Health Research Institute, which provided me with numerous tools to advance my MRP research skills. My team was working on a research project that involved developing evidence and gap maps for senior residents in long-term care, and I screened hundreds of titles, abstracts, and full texts using Covidence and EPPI Reviewer.

Other experiences over the last three years have helped build my knowledge layers about caregiving, dementia, and Indigenous peoples. Although I attended another

McMaster Indigenous Health conference in 2023 ("Indigenous Health Movement"), I also had amazing opportunities attending a policy/political conference on "Resilient Institutions; Learning from Canada's COVID-19 Pandemic" (where I sat with federal ministers and deputy ministers and their policy staff), the "Canadian Hospice Palliative Care Association Conference: A Palliative Revolution" (attending every seminar presented by Indigenous researchers), the "Canadian Caregiving Summit", and the "WALK with ME: Changing the Culture of Aging in Canada" conferences.

At every conference, I discussed my MRP project, and connections and ideas ensued. One powerful comment was by Anishinabek researcher Dr. Holly Prince, MSW, Ph.D. She stated that anybody doing research involving Indigenous peoples or issues should not offer any opinions unless they have read *The Truth and Reconciliation Commission of Canada (2015)* reports, *Canada's Residential Schools (2015)* reports, and *Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls (2019)* reports. Although I have read the reports, it certainly does not make me an expert in Indigenous issues, nor does it give me the right to an opinion. However, I have demonstrated my dedication to becoming a strong ally in the pursuit of improving the healthcare of Indigenous peoples and remain open to further learning. Although I have been encouraged to expand on my MRP literature review by applying to PhD programs and furthering my research by bringing it to Indigenous communities, I currently feel compelled to enter the workforce as a full-time policy researcher. However, I hope that the knowledge I have gained can be expanded by others interested in this area of research.

Introduction

This MRP will explore the research on people living with dementia and their caregivers within the Indigenous populations (First Nations, Inuit, and Métis) in the geographical regions of Canada. A Critical Disability Studies framework will be used to examine the intersections of dementia (disability), identity, culture, and systemic barriers in dementia caregiving.

Dementia is a neurodegenerative medical disorder of adulthood that causes a deterioration of memory and interferes with the ability to perform activities of daily living. The most common dementia is Alzheimer's Disease, but other dementias include Lewy Body, Frontotemporal Dementia, Vascular Dementia and Mixed Dementia. Young Onset Dementia sadly occurs in young adults under the age of 65 and can be caused by heavy alcohol use, brain injuries or environmental toxins. Moreover, while age, sex, and genetics are not modifiable, there are some potentially modifiable risk factors, and many social determinants of health (like culture, racism and ableism) could impact the prevalence of developing dementia (Alzheimer Society of Canada, 2024).

The irreversible cognitive impairment of dementia has a high morbidity and is the leading cause of admission to Long-Term Care (LTC). It increases the need for supervision and care due to a loss of language and communication, judgment, reasoning, and visual perception. In addition, inappropriate social behaviour may occur due to impaired motivation and emotions. In the absence of any other medical conditions, the mortality for dementia is high as the disease progresses over seven to fifteen years until death (Lyman, 1989; Dudgeon, 2010; Wong, 2016).

Before 2009, older Indigenous people had been mostly ignored in either healthcare policy forums or academic research, despite a rise in publications about younger Indigenous peoples' health. Between 1995 and 2005, only three articles of 111 focused on older Indigenous people, even though the 2006 Statistics Canada Census identified that 6.9% of the total 1,172,785 Indigenous individuals were between 55 and 64 and 4.8% were 65 and over (Rosenberg et al, 2009). Therefore, it is not surprising that Jacklin & Walker (2020) determined that very little research can provide an understanding of how Indigenous peoples define dementia. However, the limited studies suggest that dementia is typically not problematic for Indigenous peoples. This is because the Indigenous cultural perspectives of dementia do not equate the symptoms of dementia with a diagnosis of the disease. Instead, Indigenous peoples view memory loss and confusion as belonging to the circle of life and natural ageing. Indigenous peoples are known to say *'we don't have dementia here'* or have terms like *Manaakitanga* or *Aroha* that explain how ageing includes behavioural changes (Racine et al., 2022).

Johnston et al. (2020) also believe that biomedical frameworks are seen as different in many Indigenous societies that conceptualize dementia to fit within their cultural and social constructs. Furthermore, according to Jacklin & Walker (2020), decolonizing dementia's biomedical definition will require an acceptance of Indigenous views. In an early study by Hulko et al. (2010), several sharing circles and interviews were conducted with twenty-one Secwepemc Elders in British Columbia to understand differing opinions about memory loss. Traditionally, memory loss was associated with approaching the spirit world and the Creator. However, the impacts of colonization that

include dietary, environmental and lifestyle changes have introduced a fear of dementia as part of their historical trauma. The traditional view signified the pre-colonization belief that the symptoms of dementia were seen to communicate with the spiritual realm. However, the term *shémá way* (or the 'white way') was an interpretation of dementia that Indigenous seniors viewed as a terrible disease brought about by colonization and assimilation. No matter the perspective, the seniors agreed that respect and acceptance of memory loss is in keeping with their traditional views. That respect also leads to intergenerational knowledge being handed down about caregiving.

Other studies with Indigenous seniors and community participants also describe the disease as either a natural part of aging or as a part of the "circle of life." Jacklin & Walker (2020) found no studies on the Inuit's view of dementia. However, off- and on-reserve communities from Ontario, including the Haudenosaunee of Six Nations of the Grand River Territory, and rural Pottawatomi, Odawa, and Ojibwa First Nations of Manitoulin Island, used the medicine wheel and the circle of life teachings to provide context for how Indigenous peoples understand dementia. There was an acceptance of the connections between the physical and spiritual worlds throughout the aging process from birth to death.

However, Hulko et al. (2010) recognized that Indigenous communities' views on memory loss had been going through a transformation, and more Indigenous peoples were changing their understanding of dementia to include some biomedical symptoms. The consequence of the transformed viewpoints, as per Hulko et al. (2010), was that many Indigenous communities were ill-equipped to offer information and services to

those people living with dementia, and by default to their caregivers. It is then understandable that a "catastrophic event," like an injury or hospital admission, is required so that family members can voice their concerns about cognitive changes to a healthcare provider. However, the path to diagnosis remains complicated and non-standardized because of healthcare inequities and historical trauma (Jacklin et al., 2022).

More recently, according to Jacklin et al. (2023), a small sample of healthcare on-reserve formal caregivers believed that dementia symptoms do not align with the Alzheimer's Association definitions of early, middle, and late-stage dementia. Early dementia symptoms were not recognized as part of a disease, and moderate symptoms were described as early dementia by Indigenous peoples. Middle and late-stage dementia symptoms were aligned with Indigenous beliefs and their lived experience, with an explanation that a person with dementia is returning to a childhood or infancy stage.

An interesting paper by Anderson et al. (2022) discussed how the lack of knowledge about dementia amongst Indigenous people living with dementia, and their caregivers in Southwestern Ontario, was extended to a lack of advanced planning about their future healthcare goals. Without timely and accurate diagnosis of dementia, using culturally appropriate resources, patients and their caregivers are deprived of opportunities to seek support and other legal aspects of care planning, like designating a power of attorney, having assessments for Medical Assistance in Dying, or simply involving family members in their care discussions.

Indigenous ethnicity, in a study conducted in rural Saskatchewan, was associated with a decreased likelihood of people living with dementia having a Will or Power of

Attorney and social and cultural factors were named as etiological factors. Approximately 40% of Saskatchewan's population lives rurally, and at least 20% of those rural people are over the age of 65. The Indigenous population of Saskatchewan is approximately 16% (65% First Nations, 33% Métis, 0.2% and 1% other or more than one Indigenous identity), and 53% of Indigenous peoples live on-reserve. Only 9 of 82 study participants identified as Indigenous; the remaining participants were of European descent. Of the Indigenous participants, five (more than half) did not have a Will or a Power of Attorney, compared to only fourteen (of 73 people) of European descent. While Indigenous peoples faced barriers accessing the legal system due to the cost of legal services, lack of transportation to access those services and the systemic racism that has led Indigenous peoples not to trust the legal system, the authors believed that healthcare providers must discuss the importance of having these legal documents while decision-making capacity was present (Lee et al., 2019).

With so little Western medical research literature on the growing Indigenous healthcare issue of dementia, the academic community has been making efforts to fill the gaps, as evidenced in this MRP. With further research, the effects and consequences of dementia on those people living with the disease and their caregivers might be lessened. Canada released *A Dementia Strategy for Canada: Together We Aspire (2019)* report with a 5-year $50 million budget to deliver a program that would also include commitments to populations who face barriers to equitable care, specifically mentioning Indigenous peoples. Furthermore, the strategy aims to eliminate the stigma and decrease the isolation that so many people living with dementia and their caregivers experience.

Stigmatization also leads to delays and barriers for people living with dementia and their caregivers from the healthcare system, leading to inequity (Stall et al., 2019).

Unfortunately, dementia also affects the psychological, physical, social, and economic health of "caregivers for people living with dementia." It was postulated that caregivers for people living with dementia would require support to help decrease the healthcare expenditures of formal caregiving in the community and LTC (Mittleman et al., 2006). While this MRP does not focus on the healthcare costs of caregiving, many researchers have focused on reducing costs (Dudgeon, 2010).

Two separate but related searches informed this MRP. A very early literature review, summarized in the Background, explored whether caregiver stress for people living with dementia is a problem related to the symptoms of dementia, specific tasks in dementia caregiving, or caregiver attributes. Literature was chosen to critique earlier biomedical theories, and papers that discussed feminist, poststructuralist or other critical analyses or philosophies were included. A focus on the intersectionality of caregiver attributes, especially those based on gender, education, social class, race/ethnicity, and spousal/family relationships, was prioritized. This first literature review was difficult to position within a Critical Disability discourse.

While caregiving has been widely studied from a white perspective, there is minimal research on the racialized, or non-white, older caregivers. Immigrant and racialized caregivers in Canada have an increased prevalence of depression (McKenzie et al., 2016). However, the caregiver stress experienced by immigrant women was worse due to immigration policies, the lack of support from families who lived far away, and

the family's cultural expectations (Stewart et al., 2006). A gap in previous dementia caregiving studies suggests that socio-cultural theory and an intersectionality framework could capture racial and ethnic diversity and inclusivity. Furthermore, compared to white caregiver studies, there is minimal research on racial and ethnic caregivers in either rural or urban areas to provide practical, evidence-based interventions to decrease stress (Dilworth-Anderson et al., 2002; Dilworth-Anderson et al., 2020).

The realization that a gap in the literature existed regarding the Indigenous experience of caregiving for people living with dementia became the primary focus of this MRP, as it was more aligned with theories within a Critical Disability discourse.

Background

Dementia in Canada

The most often cited historical report on the status of dementia in Canada, *Rising Tide: The Impact of Dementia on Canadian Society (2010)*, was an action call to policymakers, recognizing the rising healthcare costs associated with dementia. In 2008, 103,728 new cases were diagnosed, and the prevalence rate for Canadian people living with dementia was 1.5% of the total population (a total of 480,618 people). It was expected that the number of new cases diagnosed each year would increase 2.5 times so that, by 2038, there would be 257,811 new cases. The prevalence rate would rise to 2.8% of the Canadian population (for a total of 1,125,184 people). The reason for the drastic increase is that the proportion of people living with dementia would increase as the primary risk factor for developing dementia is older age (Dudgeon, 2010).

It took the Alzheimer Society of Canada twelve years to release a report updating the Dudgeon (2010) report. The newer statistics offered in *Navigating the Path Forward for Dementia in Canada (2022)* offered projections from 2020 to 2050. However, this report only mentions "Indigenous" twice, and no statistics were provided on Indigenous people living with dementia. The updated statistics include a prevalence rate in 2020 of 1.6% but is now expected to rise to 3.6% by 2050. In 2020, the estimate was that 597,300 people were living with dementia in Canada, with 124,000 new cases diagnosed that year. Although the previous projection for 2038 was 1,125,184 people, the number of people living with dementia is now projected to increase through to 2050. By 2030, the number will rise to 187,000 new cases per year, and almost 1.7 million Canadians will be living with dementia by 2050, triple the number of 2020 (Alzheimer Society of Canada, 2022).

However, the Alzheimer Society of Canada released *The Many Faces of Dementia in Canada (2024)*. In this report, statistics included the 2016 Canadian Census of Population, with 2.1 million people (6.2% of the population) who reported Indigenous ancestry: approximately 1.5 million First Nations people, 600,000 Métis and 79,125 Inuit people. Earlier studies using 2006 census data had demonstrated that 56,400, or 4.8% of Canada's total Indigenous population, were aged 65 years or older. They also noted an increasing number of Indigenous seniors were relocating to urban areas, particularly from remote communities, although no causation was offered (Beatty & Weber-Beeds, 2013).

Unfortunately, no reliable national estimates of dementia prevalence in Indigenous peoples across Canada can be offered. However, there is a trend that suggests rates of dementia are rising in the Indigenous population more quickly than in the general

Canadian population (Alzheimer Society of Canada, 2024; Legare et al., 2019). Balestrery et al. (2019), in their three chapters on "Prevalence, Causes, and Public Discourse," recognize that prevalence rates are trending upwards, but the cause of the trend is not fully understood. In some provinces, like British Columbia, as Indigenous peoples are aging, there is a link to modifiable risk factors blamed on colonization, such as diabetes, poverty, obesity, cardiovascular disease, and low levels of education and socioeconomic status. Less common causes are the non-modifiable genetic and hereditary factors, although the higher mortality rates in young Indigenous peoples could be a factor that underestimates this particular risk.

With the caveat that Census data might underestimate the total number of Indigenous peoples living in Canada, an estimated 10,800 Indigenous people now live with dementia. By 2050, the number is expected to rise by 273% to 40,300 Indigenous people living with dementia, as compared to 187% for the general population. Unable to offer any data for the Yukon, Northwest Territories or Nunavut, the findings estimate the most significant increases in numbers for those Indigenous peoples living in Ontario and Quebec, followed by British Columbia and Alberta (Alzheimer Society of Canada, 2024).

The statement that this information "requires responses from our public health and health systems that are culturally safe and address the underlying determinants of dementia among Indigenous Peoples in Canada" (Alzheimer Society of Canada, 2024, p. 39) reinforces the research that this MRP is synthesizing. However, it is uncertain whether the Canadian healthcare system is prepared to follow through. A disheartening example is that the recent Canadian Institute for Health Information (2024) report *A Step*

Toward Understanding Health Care Trajectories of People Living with Dementia does not have a single mention of Indigenous peoples.

Defining Caregiving and Caregiver Stress

Most people who are living with dementia still live in their homes early in the diagnosis, although 85% require minimal informal assistance from family, friends, or neighbours. Support typically includes help with transportation (92%), meal delivery or preparation (88%), managing finances (92%), home maintenance (83%) or emotional support (90%). However, as the impairment worsens, 24-hour support is required to keep people safe and help with bathing and dressing, eating, or toileting (Wong, 2016). Informal caregivers in Canada, typically a spouse with an average age of 74 (46%) or an adult child (44%) that are usually daughters (71%) who live in the parental home (77%), provided 230,838,301 hours in 2008 with projections to 756,478,399 hours by 2038 (Dudgeon, 2010; Wong, 2016). The projections for 2050 recognize that over 1 million caregivers will be required by 2050 and match the tripling of the number of newly diagnosed cases of dementia, equating to an 188% increase in caregivers. The hours devoted to caregiving are now projected to be 1,385,700,000 hours by 2050, equal to 690,000 full-time jobs (Alzheimer Society of Canada, 2022).

There are mixed opinions on what defines care. Molyneaux et al. (2011) critiqued the term "care" through a historical lens and suggested that "care" is a socio-political construct, often used in healthcare research and settings. While the term "care" may be used with the good intention of promoting the recognition and support of those individuals providing care, bureaucracies have transformed a normal human experience

into an unnecessarily complex phenomenon, considering its association a burden. While informal family caregivers may socially admire the job, unfortunately, the individual being cared for is often overlooked. Furthermore, the term usually follows "informal" or "family," which in turn diminishes the significance of the work. As this work is frequently expected to be done unpaid by women, it becomes a valuable economic resource within socio-political bureaucracies. Interestingly, Dilworth-Anderson et al. (2002) had discussed that caregiving research often controlled for socioeconomic status without recognizing the intersection of race and socioeconomic status.

Fast (2015) proposed that caregiving is a significant public policy issue, given the prevailing political, socio-economic, and demographic trends in Canada, despite the multiple benefits of providing informal caregiving that often increase the quality of life for both the care recipient and the caregiver. The positive feelings of accomplishment, or an improved sense of self-worth or usefulness, have been shown to promote better mental and physical health for informal caregivers. Expanding on the motivations of reciprocity, love, and spiritual fulfillment, Brodaty & Donkin (2009) suggested that some caregivers might experience more distress due to motivations that included social pressures, guilt, a sense of duty, or greed.

To better understand the adverse effects that symptoms of caregiving stress have on the individual experience, Kim et al. (2012) focused on researching the multi-dimensional predictors of caregiver stress. Their analysis revealed three categories of predictors that can increase the likelihood of caregiver stress: disease-related factors, caregiving-related factors, and socio-demographic factors. Although a functional decline

in the care recipients (disease-related factors) explained about 16% of caregiver stress, the other factors were very close at 11% and 15%.

Financially, the direct and indirect costs of care, as well as the opportunity costs incurred by informal caregivers, would rise from $15 billion in 2008 to $153 billion by 2038. Canada's capacity to provide healthcare services, community care, and support to caregivers could theoretically overwhelm its healthcare system, given the cumulative cost of dementia over 30 years, estimated at $872 billion (Dudgeon, 2010). For example, Mittleman et al. (2006) demonstrated a 557-day delay for LTC admission if spousal caregivers received counselling and information about dementia and their caregiver role. Improving caregiver resilience through competency building and coping skills would lead to a 4.8% reduction in LTC admissions in the short term (2008-2018) and 3.2% over thirty years (to 2038). The cost savings from reducing LTC admissions would be over $12.2 billion, and the healthcare savings associated with caregiver stress would be $50.5 billion over 30 years (Dudgeon, 2010).

The potentially overwhelming healthcare costs have driven government policymakers to support research agencies that are typically supportive of biomedical research projects. Between approximately 2000 and 2010, the federal government's role in dementia research involved providing funding, ranging from $4.5 million to $20 million, through the Institute of Aging of the Canadian Institutes of Health Research (CIHR) (Dudgeon, 2010). However, Lyman (1989) suggested that the social construction of dementia and caregiving relationships requires analysis. Dementia, viewed only as a biomedical condition, brought order to dementia caregiving as defining progressive

stages led to predictability in the care required. Unfortunately, dementia does not follow the rules, and an "uncertain trajectory" leads to caregivers experiencing grief and loss long before their beloved dies. Furthermore, the power relationship of caregiving and the dependency or learned helplessness of the person with cognitive decline was not considered, even in social and behavioural science research.

The idea that keeping a person with dementia at home would decrease the impact on the healthcare system inspired researchers to examine caregiver stress. From 1984 to 1988, social gerontologists defined caregiver stress for people living with dementia through the biomedical model that focused on behavioural issues. Caregivers and those with dementia anticipated that disease progression would be associated with a "social death," and a vicious circle would ensue where caregiver stress caused an increase in control over the person with dementia. All the while, the person with dementia would lose their self-determination and increase their dependency because of anxiety, frustration, or depression (Lyman, 1989).

Whitehead (1991) states that one way to protect Canada's healthcare budget is to reduce the need for expensive formal caregiving in LTC for those people living with dementia. However, attention to health equity is required, so services for informal caregivers for people living with dementia must ensure "equal access to available care for equal need; equal utilization for equal need; equal quality of care for all." In Canada, this is challenging due to our geography and the multicultural society we live in, notwithstanding the marginalizing issues of social inequity. Furthermore, keeping a person with dementia at home decreases the impact on the healthcare system. Therefore,

it is vital to identify the vulnerable groups affected by dementia caregiving and understand the variables that cause caregiver stress.

Theoretical Approaches to Caregiving for People with Dementia

Several theoretical approaches have been utilized in the research on caregiving and caregiver stress for those people living with dementia. One model from the Research Institute for the Advancement of Women (CRIAW) attempted to capture the principles of intersectionality, which encompass gender, colonization, capitalism, racism, sexism, ageism, and homophobia, to demonstrate inequity in comparison to those who hold power, privilege, and identity (Hankivsky, 2014).

After 1988, philosophies like Michel Foucault's "medicalization of the family" were introduced, which assert that caregiving relationships become medical problems; and caregivers become "second victims" or "hidden victims," in keeping with the biomedical model of dementia (Lyman, 1989). More recently, a social model of dementia distinguished between the illness and the oppression of those with the illness. Shakespeare et al. (2019) believed a focus on the social barriers of those with dementia is preferable; however, they did not appreciate the complexity of the dementia experience on both the person with dementia and their caregivers.

Oliker (2011) examined various philosophies on caregiving, noting that feminists, gerontologists, psychologists, historians, policy scholars, economists, and sociologists have all contributed insights into the role. Then, through an intersectional sociology viewpoint on gender and caregiving, she recommended examining the relational aspects of caregiving, especially with the division of labour in the home. She also hoped that

caregivers could mobilize political support to advocate for policy centred on improving the caregiver's quality of life and health.

Dementia activism could counter the medicalization of the problem. However, the nature of the disease (the rapid progression of cognitive impairment) would hinder efforts, given the loss of capacity, loss of communication, and loss of language skills. Like those who support people with learning difficulties, caregivers could be involved in the activism since they are also living the dementia experience. Instead of defining a person by their inabilities, a relational disability model could be employed, where medical research could examine treatments. At the same time, social actions would endeavour to remove attitudinal or social barriers (Shakespeare et al., 2019). Thomas & Milligan (2018) believe that not linking dementia and disability is in keeping with the struggles of other disability movements. The social model would be an improvement over the medical model. However, it would require scrutinizing caregivers to determine if they were also inflicting disableist social barriers. If dementia were considered a disability, those people living with dementia could self-advocate and enable their identity by sharing their stories (Shakespeare et al., 2019).

As discussed in Jacklin et al. (2020), constructivist grounded theory, which is informed by Indigenous perspectives on research and anti-oppression, was used in three different research projects regarding the understanding of dementia by Indigenous peoples. Although the findings of these studies are further discussed within this MRP, briefly, they all discuss how, through sharing their stories, Indigenous peoples do not understand dementia to be a problem (Hulko et al., 2010; Finkelstein et al., 2012; Forbes

et al., 2013). Finkelstein et al. (2012) state that it is challenging to encourage Indigenous peoples to advocate for accessing care due to their understanding of dementia, as well as the stigmatization associated with the diagnosis of dementia.

Two theoretical perspectives can introduce the problems of dementia and caregiving into the Critical Disabilities discourse. First, realist theories (Marxist, critical realist, or feminist materialist) would emphasize how capitalist economies denigrate people living with dementia since they are unproductive and highlight how people living with dementia are problematic because they are dependent. They would also suggest that they be hidden at home or in some care institution that would control the person with dementia through drugs or behavioural restraints. Along with the economic argument, the cultural representation of people living with dementia would portray these people as a burden, a nuisance, or as a social problem that depletes societal resources (Thomas & Milligan, 2018).

The second, anti-essentialist (poststructuralist, feminist postmodernist, post-conventionalist) theories, would link disability and dementia through the construction of cultural meanings while defining "the normal" and "the other." This perspective would highlight oppressive ableist practices, including ageism and disablism, towards people living with dementia (Thomas & Milligan, 2018). Behuniak (2010) explains that the social constructionist or person-centred approach to dementia would empower the person with dementia instead of the caregiver. Although the loss of cognitive ability would be challenging, the loss of self would be countered by the caregiver, whose focus would support the retention of independence and functioning for as long as possible.

Furthermore, empowering the person with dementia would strengthen the connection between them and their caregiver

O'Sullivan et al. (2014) questioned why the experience of living with dementia is often found in caregiver discourse. They asked why dementia caregiving is more burdensome than caregiving for people with other chronic illnesses. Focusing on the adverse outcomes of dementia and caregiving reinforces the stigma of dementia, which focuses on feelings of embarrassment, humiliation or annoyance, leading to a sense of shame. Their research revealed that people with early dementia and their caregivers hide the diagnosis because of the stigma.

More recently, the Public Health Agency of Canada (2022) published a *Pan-Canadian Health Inequalities Reporting Initiative* on "*How to Integrate Intersectionality Theory in Quantitative Health Equity Research Analysis?*" The introduction of that report explains how racism, sexism and colonialism are "systems of domination" that are critical to the existence of each other due to their intersection. Furthermore, they jointly reinforce "the inequitable distributions of health-promoting resources and power within societies" (PHAC, 2022, p. 5). The inclusion of intersectionality in this MRP is thus essential in understanding the impacts of caregiving on non-Indigenous and Indigenous caregivers for people living with dementia.

The Intersections of Dementia Caregiving

(1) Age, Education/Employment, Gender and Spousal/Family Relationships

In 2007, Statistics Canada Eldercare reported that 25% of caregivers were over 65 and had provided care for about 6.5 years. Most caregivers over 45 had difficulty pairing

caregiving with their other responsibilities. The oldest population of people (over 80 years) was underrepresented in the data, despite this group representing the fastest growth in the caregiving population (Ghosh et al., 2020). Older caregivers for people living with dementia frequently experience challenges because they are ageing. They are at risk of developing frailty and cognitive decline or dementia themselves because of caregiving, leading to both the caregiver and their recipient requiring care (Arbel et al., 2019; Ghosh et al., 2020). The oldest caregivers also experienced significantly more mental and physical health effects and a higher risk of caregiver burnout (Williams et al., 2016).

Williams et al. (2016) discussed how lower education levels lead to increased symptoms of depression in caregivers for people living with dementia. Better physical and mental health was observed in caregivers with higher education, except for those caring for individuals with dementia. The intersections of education, employment, and social factors influence the development of caregiver stress. Furthermore, Ghosh et al. (2020) reported that regardless of women's employment or education status, they had higher burden scores if they experienced a high impact on their social life due to caregiving. Overall, women in all categories (age, education, employment) experienced the highest stress levels, and younger, highly educated, employed women were more stressed than older, unemployed women, due to competing work and caregiver duties.

Recognizing that informal dementia caregiving by women benefits the economic health of societies, Kramer (2002) and Kramer (2005) discuss why language is critical in the analysis of caregiver stress. In caregiving, if the language suggests that caregiving is stressful, then the knowledge (or research questions) will reflect that assumption.

Unfortunately, women also describe themselves in gender traditional terms, using words like "caring," "compassionate," or "selfless," ascribing their role to duty or obedience, all associated with traditional gender identity traits. Given that caregiving is often relegated to the female gender, in feminist theory, it is devalued and therefore undesirable. These papers revealed a gap in the literature, in that representations of positive caregiving experiences were lacking and should be included in future research.

Hooyman & Gonyea (1999) argue that feminist theory provides us with further understanding of the gender-based caregiving issues by challenging the societal attitudes and behaviours that subjugate women at home and in the labour market. Historically, societal expectations were that women would be the primary caregivers while ignoring caregiving's adverse economic or emotional effects. A feminist model would empower women to choose whether or not to provide caregiving, with the expectation that "gender justice" would follow.

Women caregivers have a higher risk of medical co-morbidities and chronic illnesses regardless of the recipient's diagnosis. Furthermore, if dementia caregiving, women have a higher risk of symptoms of depression and anxiety typical of caregiver burden. In contrast, men experience fewer symptoms because they often secure outside assistance in managing their caregiver responsibilities (Williams et al., 2016).

Few studies suggest that men are embracing caregiving. Robinson et al. (2014) report that, in Canada, 40% of men provided dementia caregiving before 2010, related to an increased prevalence of dementia in women. However, the transition from conventional masculinity, which values traditional breadwinner roles and responsibilities

with gendered divisions of labour, to "woman's work" is stressful to men who sometimes refuse caregiving tasks considered as nurturing. Men also tend to underreport emotional burden due to gender constructs but do report high levels of physical stress or illness. Interestingly, studies reviewed by Robinson et al. (2014) did not use a gender framework in their design or analysis despite providing examples to understand gender differences in caregiving, including how male caregivers relate to their care recipients. Some men experienced personal reward through caregiving, believing they were enhancing the quality of life for their loved ones. Calasanti & Bowen (2005) believe that a more inclusive definition of caregiving should encompass not only physical well-being but also the emotional responsibility caregivers assume for their care recipient.

A 2014 Canadian study was undertaken to determine if the spousal relationship or the behaviour of the person with dementia affected the health of the caregivers for people living with dementia. Like other studies, wives had increased stress levels and poorer mental and physical health, and significant differences were seen in the premorbid relationship with their spouses. In addition, women were more pessimistic about their spousal relationship and had higher stress attributed to challenging or aggressive behaviours by their demented spouse (Gibbons et al., 2014). Then, a scoping review by Arbel et al. (2019) on gender differences in spouses' dementia caregiving determined that women had more depression and stress, but this was not attributable to dementia caregiving. Interestingly, no studies have examined the positive aspects of caregiving identified in other research as an essential mitigating factor for caregiver stress.

Chappell et al. (2015) discuss, in their study of gender and relationships in dementia caregiving in British Columbia, how the intersectionality theoretical framework recognizes the complexity of caregiving variables. Their framework integrated social conditions experienced by caregivers, their care recipients and other family members. Almost all the caregivers in this study (95.7%) were white, and there were no Indigenous peoples. Seventy percent of the caregivers in the sample of 873 were female spouses. However, the care recipients were evenly distributed between men and women. Husbands had the lowest levels of stress. The highest level of caregiver stress was among women, especially daughters, especially if they had higher levels of education. This study also examined self-esteem indicators. Self-esteem was highest in educated daughters and lowest in female spouses with less education. Only men who had poor relationships with the care recipient reported lower self-esteem.

More recently, Kokorelias et al. (2021) interviewed equal numbers of female/male spouses who are caregivers for people living with dementia to determine intersectional gender and relationship type issues. The acceptance of a dementia diagnosis was difficult for spouses. Men felt guilty for being unaware that a medical diagnosis was responsible for the changes they were seeing. In contrast, wives remained skeptical and, through denial, questioned the physician's capacity to diagnose.

Caregivers for people living with dementia are at a higher risk of experiencing stress and burden, especially if there is family conflict. Furthermore, in addition to poor physical health, caregivers for people living with dementia reported more mental health issues, including increased depression and anxiety and decreased well-being. A

mitigating factor that decreases caregiver stress is healthy family dynamics and high family cohesion (Hilgeman et al., 2009; Williams et al., 2016; Sheehan et al., 2020)

Other research on dementia caregiving highlights the challenges wives and daughters face when caring for a family member. Peacock et al. (2020) were interested in Wuest's (2001) feminist theory of women's caregiving because it reflects the social, emotional, physical, and relational factors in providing care. Overall, daughters consistently experienced the most significant caregiver stress when they were employed. Caregiving challenges included other employment and household duties, the loss of social time with others, financial burdens, and the recipient's behaviours from dementia (Peacock et al., 2020; Kokorelias et al., 2021).

Cheng (2017) found that disruptive behaviours, like aggression or disinhibition, predicted higher levels of caregiver stress and symptoms of depression in the caregivers for people living with dementia. These behaviours disrupt the emotional relationship and connection between the caregiver and care recipient, and they also interfere with the provision of care in activities of daily living. That might explain why Kokorelias et al. (2021) found that wives wanting control over their spouses' care was a consistent theme, in line with the biomedical models of caregiving. Wives preferred assistance with home-related tasks, such as housekeeping, whereas husbands preferred leaving personal care to other support workers. Sons and daughters were comfortable allowing outside workers, and sons were very uncomfortable performing personal care. Again, wives and daughters reported an inability to balance their social life with caregiving. Moreover, although no

direct relationship between gender and relationship type was found, the complexity of family relationships in caregiving was highlighted.

Fletcher (2021) found that family members quickly determine their inability to share caregiving activities when they conform to gender norms or personal qualities, thereby confirming others' capability for providing care. Despite lacking the male primary caregiver's perspective, family members often manipulated their relatives using gender roles when presented with caregiving situations instead of recognizing the social structures contributing to traditional informal caregiving. Since most research focuses on the primary caregiver, there was a need to elicit the perspectives of other family members who used competing priorities or geography to avoid dementia caregiving. A lack of gender analysis does not necessarily weaken an argument for gendered caregiving, but it was surprising, given the focus on intersectionality in recent research.

(2) Race, Ethnicity and Culture

Arbel et al. (2019) revealed that sociodemographic data were limited throughout their scoping review. It was difficult to comment on intersectionality issues like ethnicity, income, and education because participants were mainly middle-class, highly educated and white. In addition, significant gaps in ethnic or cultural minorities were evident in dementia caregiving studies, and people in non-traditional relationships were never represented. There was a lack of older caregivers with unique ageing concerns (Larkin et al., 2018; Arbel et al., 2019).

A conceptual intersectional framework to study dementia caregiving across time or illness trajectories was an exciting suggestion. Previous intersectional studies have

often disregarded the stage of dementia, possibly due to the biomedical approach of staging or because a large-scale longitudinal study would be required to yield meaningful results (Gallagher-Thompson et al., 2019). A thorough scoping review would be required to determine if caregiver stress for people living with dementia is a problem related to the symptoms of dementia, specific tasks in dementia caregiving or caregiver attributes in Canada. An Intersectionality Framework that includes looking at the stigma, the very old caregiver, ethnic and racialized minorities, caregivers in the LGBTQ community and family relations would provide a more accurate picture of the dementia caregiving experience in Canada; and a critical analysis of the problematization of disableism in dementia would advance the topic within a Critical Disabilities discourse.

However, the literature gap that most excited me when choosing a topic for my MRP was introduced by Jacklin et al. (2015), who explained how the prevalence of dementia rose quickly among Indigenous people in Canada since 2000. However, support services providing Indigenous caregivers with respite or information about Dementia were lacking. Cultural values, traditional beliefs, and historical experiences were an influence on dementia caregiving practices in Indigenous communities. Furthermore, they explained that caregiving is a shared family experience designed to alleviate the burden on an individual, and they reported that the experience is unlikely to produce negative emotions, as younger Indigenous people tend to experience greater satisfaction due to the solid relationships they develop with their elders. However, Jacklin et al. (2015, p. 107) remind us that those changes in family dynamics resulting from

colonialism and urban migration, which elders refer to as the "big change in culture," are surely likely to alter caregiving dynamics.

Research Questions and Methodology

Research Questions:

Since 2020, research has been published on Indigenous caregivers for people living with dementia in Canada (Parrack et al., 2020; Bourassa et al., 2021; Racine et al., 2022; Ward et al, 2023). Furthermore, the health, economic and social challenges unique to Indigenous peoples have been examined, so the effects of poverty, intergenerational trauma and limited access to culturally appropriate care services can be reviewed.

This MRP primarily sought to determine what research on Indigenous peoples living with dementia and their caregivers in the geographical regions of Canada has been carried out. However, the following questions would become themes for the research:

(1) What has research determined to be the sources of caregiver stress experienced by Indigenous people living with dementia and their caregivers in the Indigenous communities within the geographical regions of Canada?

(2) How do the community, cultural and spiritual practices shape the experience of Indigenous people living with dementia and their caregivers? Have any coping mechanisms been identified to help Indigenous people living with dementia and their caregivers manage stress?

(3) What role do the ongoing experiences of colonialism, marginalization and systemic inequities play in the stress experienced by Indigenous people living with dementia and their caregivers?

(4) How could Indigenous Ways of Knowing help with the development of caregiving support models that would be culturally relevant and address the needs of Indigenous people living with dementia and their caregivers?

(5) What gaps remain in the existing literature on Indigenous people living with dementia and their caregivers?

Theoretical Perspectives

The Critical Disability Studies framework examines disability as a social construct rather than as a medical condition. The framework also critiques existing medical models of disability, realizing that policies, societal structures and cultural norms contribute to the oppression and marginalization of all disabled individuals and their caregivers. In this research, the Critical Disability Studies framework will inform a discussion about how dementia, caregiving for people with dementia, and Indigenous identity intersect, considering historical trauma, cultural practices, and colonial legacies (Barker & Murray, 2010; Cleall, 2024).

Indigenous research methodologies can build upon the transformative and critical approaches of Eurocentric research, thereby advancing the field. This is achieved by recognizing the self-determination of Indigenous peoples and supporting their leadership in all aspects of conducting research—namely, the conceptualization, methodology, interpretation, and dissemination of research (Braun et al., 2014).

The inclusion of Indigenous Ways of Knowing, as well as decolonizing methodologies, will advise the research, emphasizing community engagement, relationality, and respect for Indigenous cultural values (Bourassa et al., 2015; Gurung,

2024). However, a Narrative Review methodology will synthesize the studies focused on Indigenous people living with dementia and their caregivers, enabling the identification of patterns or trends, and gaps in the research (Kovach, 2021; Smith, 2021; Hall, 2024).

This MRP has included Decolonizing Theory while it analyzes the intersections of dementia, caregiving for people who live with dementia, Indigenous identity, age, gender, and family relationships. Decolonizing studies can transform the approaches that Eurocentric research has traditionally taken. Likewise, exploring the connections between disability, colonialism, and systemic inequities can give a voice to Indigenous knowledge systems and other oppressed peoples. Just as Critical Disability Studies aim to combat the marginalization and stigmatization of people with disabilities, Decolonizing Studies can oppose the ableist beliefs that colonial processes have ingrained. Therefore, decolonizing disability studies requires interruption of the Western dominant views to make room for postcolonial, intersectional and Indigenous perspectives (Roy, 2024).

Related to Decolonizing Theory, Postcolonial Theory has recently been offered as an explanatory framework for Canadian healthcare providers practicing with Indigenous peoples. This theory proposes that providing healthcare to Indigenous peoples requires an understanding of the postcolonial relationship between Indigenous peoples and the Canadian settlers. Postcolonial Theory provides the basis for much cultural safety training. However, it requires an expanded profile to combat the ignorance and prejudice that Indigenous peoples are subjected to in the healthcare system (Wilmot, 2021).

Cleall (2024) explains how the intersection of postcolonialism and disability studies is producing new and exciting research opportunities. She explains that

postcolonialism can provide a language to explore the fluid and shifting discourses that has permeated disability research, particularly in its intersectional approach to areas such as race and gender. The intersection of postcolonialism and disability studies might tackle the "highly emotionally charged" discourses that have traditionally portrayed disabled people, and likewise Indigenous people, to offer different viewpoints with a more "complex tapestry" (Cleall, 2024, p. 11).

Research Methodology

This MRP included a literature search from 2000 to 2025, recognizing that anything written prior to 2015 might be more helpful in providing background information. A combination of inclusion and exclusion criteria was used to identify relevant articles. To be included in the MRP, the research required a focus on Indigenous (First Nations, Inuit and Métis) people living with dementia and their caregivers in any geographical region within Canada. It could employ qualitative, quantitative, or mixed-methods studies. Any literature that did not address Indigenous caregiver stress but discussed Indigenous people living with dementia was analyzed, as it might inform either the background or the discussion sections of the MRP.

Exclusion criteria included research focusing on non-Indigenous populations or generalized dementia caregiving, as these studies were a part of the background review, and they had failed to address Indigenous people's experiences. Studies published in languages other than English or without accessible translations were discarded.

The primary search strategy included electronic databases through my accounts with McMaster University and York University. Independent searches of both libraries

were conducted and found to be identical, utilizing PubMed, Google Scholar, Scopus, CINAHL, and JSTOR. The key search terms that delivered the most research literature were "Indigenous and Dementia and Caregivers." Categorizing Indigenous peoples into First Nations, Inuit, or Métis did not yield further results. Other search terms, such as "cultural caregiving" or "dementia caregiving in Indigenous communities," yielded no additional findings, nor did using the word "aboriginal" instead of "Indigenous." The 144 papers, posters, abstracts, reports, and books underwent title analysis, scanning and removing duplicate entries, or abstracts and posters from conferences that lacked a related study. The remaining 128 pieces of literature underwent a second scan to remove those that were not specific to Indigenous people in any geographical region within Canada, leaving a total of 43 papers, reports, and book chapters. These 43 pieces of literature were then downloaded and saved to either Mendeley Reference Manager or a backup file folder if Mendeley would not attach the PDF.

A second search was done using Google to find any additional grey literature or studies not found during the searches through McMaster University and York University. Twenty-two (22) studies and reports were generated through this search, and almost half provided background information or knowledge regarding postcolonial or decolonizing theory. These studies were also downloaded and saved to either Mendeley Reference Manager or a backup file folder if Mendeley would not attach the PDF.

The final decision on inclusion in the Review section of the MRP would be made after reading the abstracts, introductions and conclusions to determine that they were related to the research questions and themes. The use of labels and folders in Mendeley

was used to organize papers as they were read and coded into the themes for review and discussion. Furthermore, suppose the literature was not directly related to Indigenous people living with dementia and their caregivers but provided information related to Indigenous theoretical approaches or Indigenous Ways of Knowing. In that case, it might be included in the background information, the research methodology or the discussion, as long as it was related to Indigenous peoples and their health.

Finally, a total of 56 pieces of literature about Indigenous peoples were used in the writing of this MRP, in addition to the 41 pieces of literature reviewed for the Introduction and Background sections. Of the 56 pieces of Indigenous-related literature, there were two non-peer-reviewed articles, 38 peer-reviewed articles, eight books/chapters, five reports, and three theses.

Results

The results of the Literature review are presented through six themes that are related to the secondary research questions from the Methodology section.

How Colonialism, Marginalization and Systemic Inequities Create Stress for Indigenous People Living with Dementia and their Caregivers?

Five studies (MacDonald & Steenbeek, 2015; Mitchell et al., 2019; Gaspard et al., 2021; Racine et al., 2022; Ward et al., 2023) introduced how colonialism, marginalization and systemic inequities create stress for Indigenous people living with dementia and their caregivers. While these studies were specific to the topic of dementia and caregiving, these concepts will be expanded on in the theoretical discussion to follow.

An interesting theme to emerge from a research study with Gitxsan Indigenous peoples in British Columbia was the loss and grief that were different for Indigenous

people living with dementia and their caregivers. There were expressions of loss associated with colonization, such as the loss of identity and community role (e.g. chief or elder), the loss of stories and traditional knowledge, the loss of spiritual bonds with traditional lands and a loss of history. Furthermore, there was grief for those who might have died decades earlier with dementia, linked to colonial and historical trauma, with a recognition that the effects of colonization are ever-present (Gaspard et al., 2021).

Although all the studies discussed colonial trauma, Mitchell et al. (2019) remind us that colonial trauma has individuals living in a location together, while they remain separated from their cultural traditions. Therefore, fewer people are fulfilling their ancestral responsibilities, duties and roles that are essential to the well-being of Indigenous peoples in their communities.

MacDonald & Steenbeek (2015) state that understanding the experience of Indigenous (First Nations, Inuit and Métis) people living with dementia and their caregivers requires an examination of the aspects of Indigenous life that were impacted by colonization and government assimilation, in particular, socio-economic conditions, healthcare, culture, traditional roles, access to services and equity. Furthermore, the identification of how Western research has negatively impacted Indigenous peoples' spirituality, politics, economy, and history through postcolonial theoretical perspectives can lead to more respectful practices of decolonizing research. Moreover, Racine et al. (2022) believe that decolonization is required to understand how Indigenous peoples view dementia. The non-Indigenous views of dementia as a sign of weakness, along with

its associated stigma, likely inhibit Indigenous people living with dementia and/or their caregivers from accessing any Western healthcare or support organizations.

All the family caregivers in the Ward et al. (2023) study told how they were subjected to racism. Many told stories about how healthcare providers "accused" them of not caring for their family members appropriately. The caregivers understood that they were being treated differently from non-Indigenous caregivers, especially in their ability to access support promptly. Furthermore, they told of racist experiences related to the social determinants of health, such as safe housing and water, poverty, or lack of trust in the Western healthcare system.

Indigenous Ways of Knowing and the Development of Caregiving Support Models

By far the most significant volume of studies, spanning 12 years of research, demonstrates how Indigenous ways of knowing have informed the development of caregiving support models. Eleven studies (Forbes et al., 2013; Alcock, 2019; Starblanket et al., 2019; Bourassa et al., 2020; Jacklin et al., 2020; Johnston et al., 2020; Webkamigad et al., 2020; Legare, 2021; Racine et al., 2022; Shrestha & Shrestha, 2023; Illes et al., 2025) were reviewed for this section, and the majority have been published in the last five years.

The Health Council of Canada (2012) identified multiple healthcare inequities affecting Indigenous peoples and emphasized the importance of developing Indigenous approaches to health literacy. The cultural safety model highlighted health disparities in Indigenous communities that stem from historical, colonial, and sociopolitical factors (Webkamigad et al., 2020; Racine et al., 2022).

Fixing health inequities for people living with dementia and their caregivers would occur through education and lead to system change (Johnston et al., 2020; Webkamigad et al., 2020). Racine et al. (2022) discuss that, as research about cultural safety has exploded, it has described the integration of Indigenous ways of knowing in research to change healthcare delivery. In research on caregiving for those people living with dementia, cultural safety recognizes the effects of colonization and historical trauma in the present day. It also understands that there are different ways that Indigenous peoples understand assimilation and colonization, and therefore various ways of experiencing caregiving. To provide culturally appropriate care, culturally adapted tools must be used not only to diagnose and treat those living with dementia, but to recognize caregiving issues. Furthermore, to treat Indigenous people living with dementia, the wisdom of elders and honouring traditional healing practices must be valued, as it is a way to reposition the dementia discourses.

Two studies provided information about how cultural safety is a crucial component of ethical research with Indigenous peoples, as it can ensure that functioning relationships with the communities are prioritized. The critical elements to create a safe environment are humility, cultural competency, and relevance, and researchers and healthcare professionals need to develop decolonized perspectives to avoid further racism. The relevance of culture determines whether programs and services effectively incorporate relevant aspects of traditions, practices, and beliefs. Many examples in Canadian Federal government policy fail to incorporate cultural relevance regarding

Indigenous culture and traditions, resulting in systematic racism (Racine et al., 2022; Bourassa et al., 2020).

Bourassa et al. (2020) explain how cultural safety involves deconstructing present systems that perpetuate ethnocentric viewpoints and ideas, which are prevalent in the research and healthcare fields. Adhering to the practice of cultural competency is likewise essential, and this involves reconsidering attitudes, knowledge and skills that an individual possesses. Thus, to achieve cultural competency, it is necessary to look beyond any biases and analyze or criticize your own culture. The goal of cultural competency is not to become competent in the culture of other people, nor is it to highlight the differences between cultures. Therefore, researchers must be able to reflect (critically) on their research processes.

Closely related to cultural safety is the decolonizing framework of Two-Eyed Seeing or *Etuaptmumk*, discussed in 4 studies. This framework was proposed in 2004 by two Mi'kmaw elders from Eskasoni First Nation (Cape Breton) in Nova Scotia, Albert and Murdena Marshall. It explains how there are many ways of understanding the healthcare world, including the Western biomedical model, and the various knowledge systems used by Indigenous peoples. Furthermore, acknowledging and respecting diverse perspectives through this framework is to impede the dominance of one idea over another (Illes et al., 2025; Racine et al., 2022; Webkamigad et al., 2020; Alcock, 2019).

Illes et al. (2025) believe that many novel approaches to pedagogy and academic scholarship are rooted in Indigenous ways of knowing. Indigenous peoples have been practicing land-based education, community-led inquiry and experiential learning,

restorative rather than punitive approaches to misconduct, emphasizing social relationships and connections for centuries. Although non-Indigenous peoples can choose to engage with Indigenous knowledge systems as a principle of reciprocity, there has been an imbalance towards Western knowledge for Indigenous peoples. However, now that academia is discussing Two-Eyed Seeing, it will be essential to recognize why it is not being used in human research and caring. Illes et al. (2025) suggest

> "There would seem to be a litany of reasons: ongoing oppression and marginalization of Indigenous peoples in many societies and scientific communities, individual and systemic epistemic arrogance in which only the Western way of knowing is perceived to be of value, lack of knowledge of other knowledge systems, lack of relationships with Indigenous partners that has been fuelled in part by the exclusion and marginalization of Indigenous scholars in academia, challenges to identifying ways of decolonizing or Indigenizing a particular area of study and fear of consequences for making mistakes or causing offence, among others.

Forbes et al. (2013) devised a model of 'dementia care knowledge' that can lead to shared knowledge between informal and formal caregivers, enabling professional healthcare providers to develop care strategies that help break down cultural barriers. In this model, healthcare professionals gather knowledge from caregivers and those living with dementia, including their understanding of symptoms, signs, risk factors, and treatments, while also offering formal assessments and treatment. Incorporating the language, values and beliefs of the Indigenous people would aid in the development of a therapeutic relationship based on trust, thus alleviating fears about assessments and diagnosis. Moreover, Webkamigad et al. (2020) employed a Two-Eyed Seeing framework to develop health promotion materials about dementia and subsequently ensured that Indigenous communities could provide consultation regarding their

usefulness. This approach acknowledged that both the Western biomedical model and Indigenous ways of knowing possess strengths, and that combining these ideas could lead to the creation of culturally safe materials.

Jacklin et al. (2020) state that commonly used cognitive assessments in Canada, such as the Montreal Cognitive Assessment (MoCA) or Mini-Mental State Examination (MMSE), are not culturally appropriate for use with Indigenous peoples as they fail to account for the effects of colonization and the health and social inequities that have followed. There is only one more culturally safe and appropriate screening tool that was developed in collaboration with Indigenous peoples in Australia, called the Kimberly Indigenous Cognitive Assessment (KICA). The assessment tool employs a Two-Eyed Seeing approach between Western biomedical and Indigenous knowledge.

Jacklin et al. (2020) highlight significant differences in most aspects of Indigeneity between the Australians and North American Indigenous peoples. However, they determined that the KICA should be studied with the Anishinaabe First Nations communities in Manitoulin Island to assess the validity of the assessment tool for use with the Anishinaabe population. The Manitoulin Island region is home to seven First Nations communities and three First Nations Health Authorities. The 4500 Indigenous peoples are mostly Ojibwa, Potawatomi and Odawa and live on-reserve. As there was a mix of English and Anishinaabe language represented, the discussions and assessment questions were translated, as language changes are often related to dementia. The results found that the KICA could be adapted as a culturally safe assessment tool used by a

practitioner who understood their historical trauma and respected the impacts of colonization and their cultural spiritual beliefs (Jacklin et al., 2020).

As discussed by Shrestha & Shrestha (2023), the development of a culturally safe assessment tool would be in keeping with a recent concept, *culturally safe dementia care (CSDC)*, which is meant to empower Indigenous peoples. The CSDC is in keeping with the Indigenous idea of empowerment in healthcare and aligns with the World Health Organization's policy of recognizing Indigenous community members and leaders as critical to bridging an equity gap in dementia care.

Legare (2021) explains how Morning Star Lodge, an Indigenous Health Research lab in Treaty 4 territory, in Regina, Saskatchewan, developed workshops for Indigenous seniors at risk for developing dementia and their caregivers. Participation in traditional activities included prayer (smudging), arts and crafts, and games. Traditional ways of knowing and teachings were woven into the social interactions through storytelling, and caregivers found this helpful in decreasing their stress.

The Morning Star Lodge appears successful in developing the authentic relationships and transparency required to create a safe space for working with the Indigenous peoples it intended to serve. This was achieved by investing time learning about the community's protocols, history and ceremonies while using a mentorship model that promotes cultural safety and resists hierarchies that lead to multidirectional learning. The lab refers to researchers and participants as co-researchers to balance the power that has typically been present in Western research. Furthermore, the lab is careful

to focus research results as specific to the region and the people it is engaging, as Indigenous peoples and communities are not homogeneous (Hutchinson et al., 2023).

Another example of conducting research with Indigenous peoples was a collaboration of Aging Technologies for Indigenous Communities in Ontario (ATICON) and the Community Advisory Council (CAC) of Anishinaabe elders, language experts, caregivers and healthcare providers of the seven First Nations of Manitoulin Island, discussed in Jacklin et al. (2020). A new product, the CareBand, using wireless technology, was a wrist band developed to capture movement-related behaviours in people living with dementia that include wandering, agitation and falls. The downloadable data could be used by healthcare providers and caregivers of people living with dementia. Using Indigenous protocols for the development and management of research that included respect, relevance, responsibility and reciprocity, the focus group sessions indicated both positive and negative feedback. The aesthetics of the wristband would require some changes to be more reflective of the culture, and it would need to be cost-efficient (i.e. government-funded). Furthermore, privacy issues about the data were problematic given the lack of trust most Indigenous peoples have in healthcare services. However, caregivers agreed that the CareBand would improve their 'peace of mind' once the technology addressed aesthetic, privacy and access issues (Jacklin et al., 2020).

Starblanket et al. (2019) determined that the increased use of technology has been touted in promoting independent living, improving cognitive functioning, and decreasing caregiver stress. As Indigenous seniors prefer to live at home and not be admitted to long-term care, technology might provide more time at home. The caution remains that any

technology must be developed in collaboration with the users. Furthermore, it needs to be culturally appropriate and available. Their study of 43 caregivers for people living with dementia in the File Hills Qu'Appelle Tribal Council in Saskatchewan was developed through the Health Research Lab (Morning Star Lodge). Findings were generally positive, although stable Internet access was not available and, therefore, frustrating for the participants. Furthermore, without stable Internet and computer knowledge, their caregiver stress was not reduced.

The sources of Stress for Indigenous People Living with Dementia and their Caregivers

In this third theme, looking at the sources of stress for Indigenous people living with dementia and their caregivers, seven studies were reviewed for their discussions of the sources of stress for Indigenous people living with dementia and their caregivers (Buchignani & Armstrong, 1999; Krieg et al., 2007; Hulko et al., 2010; Finkelstein et al., 2012; Habjan et al., 2012; Forbes et al., 2013; Webkamigad, 2017).

Before the year 2000, no Canadian studies focused on caregiving for older Indigenous peoples. Although studies were published in the United States, their service delivery systems and the living patterns of Indigenous peoples in the US were so different that the data were deemed irrelevant to the Canadian context (Buchignani & Armstrong, 1999). Buchignani & Armstrong (1999) studied informal caregiving in their *Alberta Native Seniors Study*, sampling 858 people (69% status First Nations and 28% Métis) aged 50 and older, with an average age of 63 years. Indigenous women were the primary caregivers in most circumstances, like in traditional times, where caregiving to the seniors in their family was framed as the ethical and desirable effect of living in an

Indigenous community. In more recent times, that same family obligation has been viewed as a key factor in caregiver stress that leads to lower self-esteem, depression, and lower life satisfaction among Indigenous women.

In another study by Krieg et al. (2007), Indigenous people living with dementia were deemed to be dependent on informal care from immediate and extended family members due to the lack of healthcare services, especially in more remote communities. In a Northern Saskatchewan First Nations Community, family caregiving was thought to compensate for disparities in economic resources, while caregivers were assisting with daily tasks and addressing the mental and social needs of the Indigenous people living with dementia. However, suppose the family was unable to provide all the caregiving support. In that case, those living with dementia might not have access to community support and resources and lack the safety net required to remain in their community.

Historically, many Indigenous communities were not equipped to offer information and services to those people living with dementia or their caregivers. With conflicting viewpoints about dementia, information about its risk factors, progression, symptoms, and treatments might add to the difference between the *shémá way* and the Western biomedical system (Hulko et al., 2010; Finkelstein et al., 2012). Earlier studies (Forbes et al., 2013; Webkamigad, 2017) determined that the problem with providing accessible information about dementia is that Indigenous peoples lack trust in information that has come from the Western medical system. The language used in health promotion might not be presented in a culturally safe manner. Likewise, non-Indigenous health professionals might not be trusted, regardless of the materials they provide,

especially if they are generic and not inclusive of local content. Forbes et al. (2013) emphasized the importance of healthcare providers being consistent in their care, as the legacy of mistrust is very difficult to counter, and this extended to consistency and sustainability of community programs.

Habjan et al. (2013) recognized that a primary barrier to accessing quality healthcare is the scarcity of healthcare professionals who speak Indigenous languages. They quote findings in the 2007 First Nations Regional Longitudinal Health Survey that found 22.3% of the Indigenous population primarily used their First Nations language to communicate. However, only 2.25 were unilingual and lacked fluent French or English. The combined lack of culturally appropriate and safe care, combined with healthcare professionals' inability to speak the required Indigenous languages, leads many senior members to bypass formal healthcare systems (Habjan et al., 2012; Forbes et al., 2013).

Although Canadian medical schools have introduced strategies to increase the representation of Indigenous students that could increase the number of Indigenous speaking healthcare providers, Brisebois & Cardinal (2024) determined that Indigenous students from rural and Northern communities, and reserves, are under-represented. However, despite little effect on First Nations and Inuit students, increasing numbers of Métis students are being admitted, likely in keeping with their increased completion of bachelor’s level education, which is a prerequisite to medical school admission.

The Intersections of Indigenous People Living with Dementia and their Caregivers

Like the third theme, this theme discusses the intersections of Indigenous people living with dementia and their caregivers. Seven papers were reviewed (Buchignani &

Armstrong, 1999; Crosato et al., 2007; Krieg et al., 2007; Habjan et al., 2012; Bourassa et al., 2015; Legare et al., 2019; Parrack & Joseph, 2020).

The background section of this MRP determined that caregiving often falls to the women within families of non-Indigenous Canadians. Despite the accuracy of census information about Indigenous women, along with non-Indigenous women, they are typically responsible for childcare, meal preparation, housework and caregiving to older family members. For many Indigenous families, domestic obligations are an integral part of their culture. Métis women define health and wellness by their ability to be family caregivers (Legare et al., 2019; Parrack & Joseph, 2020).

Parrack & Joseph (2020) discuss that, although Indigenous women are predominantly family caregivers, unlike non-Indigenous people, there is little difference between genders in those reporting providing care to seniors. Approximately 20% of Indigenous men and approximately 24% of Indigenous women were providing informal care to seniors in a 2001 survey. Furthermore, at least 5 hours of weekly care were provided to seniors by 49% of Indigenous men and 52% of Indigenous women. Approximately 72% of Inuit and Indigenous women living on-reserve were the caregivers of seniors, spending less than 10 hours weekly. These same women were also providing childcare at higher rates than non-Indigenous women (54% spending more than 30 hours per week), as the Indigenous women were considerably younger than their non-Indigenous counterparts. Childcare was cited as a time constraint for other caregiving.

In their interviews with Indigenous women in ten isolated communities in northern and southern Ontario, Crosato et al. (2007) concluded these caregivers were

aware of the context in which they were providing care. The term "caring" was used instead of "caregiving," as it is the word participants used to describe their experiences. In their Indigenous communities, they were seen as healers within their families, with a connection to their Indigenous community. The circle of care was noted to be closed, as this task was not open to all family members, and they were somehow chosen to walk through the door because of their strength. The women explained that role-modelling was used to teach younger girls and women how to provide care and to pass on the tradition.

However, according to Crosato et al. (2007), their circles of care also occurred within their non-Indigenous communities, signifying where external resources and services lived. Being dependent on non-Indigenous healthcare providers and services was fraught with problems. This is the circle that had brought about racist policies of assimilation, and many were aware that the residential school experience was still impacting their values and traditions, as most were raised by parents who had no connections to their culture.

Although the Buchignani & Armstrong (1999) study falls just outside of the inclusion criteria for this MRP (2000-2025), and its data is outdated, it was the only study regarding Indigenous caregivers that provided some historical data about their education and economic status. They demonstrated that most Indigenous seniors in Alberta were ill-prepared for living independently as they aged, and I will assume that there has been no significant change. Financially, these Indigenous people were poor as their monthly income averaged only $860 ($912 for men and $827 for women), compared to that of similar-aged non-Indigenous Albertans, whose monthly income was $2,335 for men and

$1,220 for women. At the time, the 'poverty line' was $1,180 per month. Furthermore, education and employment levels were very low. Indigenous seniors had only five to six years of formal education compared to non-Indigenous seniors who had at least 10 years of formal schooling. Only 17% of those between 50 and 64 were employed, and those jobs were poorly paid, informal or episodic, and without any pensions or benefits.

Parrack & Joseph (2020), in their review of caregivers for Indigenous seniors, determined that higher unemployment rates have been standard among Indigenous women, even if 50% of those women (aged 45 to 64) were working. However, unlike their non-Indigenous counterparts, 60 percent of Indigenous women are employed in the lowest-paying occupations, whether they work in the finance, administration, sales, or service sectors. Working in these sectors has limited benefits, and Indigenous women have had reduced flexibility in their ability to manage unpredictable care crises or to arrange care services during regular working hours.

Indigenous women fortunate enough to be employed might bear similar high economic costs associated with caregiving as their non-Indigenous counterparts. Taking extended leaves to be a caregiver could also be significant by impacting their pensions, benefits, and financial independence, and ultimately affecting their quality of life. Younger generations of caregivers would also be impacted if they sacrificed educational opportunities while providing unpaid caregiving. However, the conclusion offered was that any program developed for Indigenous caregivers would be ineffective if they did not use a cultural lens in their development (Parrack & Joseph, 2020).

According to Habjan et al. (2012), unfortunately, like some non-Indigenous caregivers, Indigenous family caregivers find themselves forced to choose between caring for their elders and fulfilling personal obligations, such as the wishes of their other loved ones or work. Therefore, some Indigenous communities find it necessary to rely on formal caregiving services or facilities. Although some family members acknowledged a need for formal caregiving support, they also recognized how the family was forced to be more involved in caregiving because those formal supports were lacking or nonexistent. Other Indigenous families believed that, even if available, formal caregiving support was not the solution, as the care was rarely culturally relevant and safe.

Krieg et al. (2007) discuss how the senior Métis women living in the remote or northern communities of Saskatchewan are mainly dependent on their families to provide care, as these communities lack healthcare services and there is typically no long-term care available. Their marginalization is characterized by physical and social isolation, and many people living in these most remote communities live in extreme poverty. This study was a reminder that despite an expectation of being a caregiver, these same women also require care as they age.

To understand the intergenerational effects of colonization, Bourassa et al. (2015) focused on Indigenous women, as they are the primary caregivers in their communities. Indigenous women are also the most marginalized in Canada, as evidenced by the fact that they are the poorest and experience more ill health and violence than non-Indigenous women. This is credited to colonization, as they have suffered a loss of culture and a breakdown of families from the continued impact of the residential schools. The

intersection of sexism and racism has therefore created greater inequities for Indigenous women, and their situation has caused political, social and economic barriers both outside and inside Indigenous communities.

The Community, Cultural and Spiritual Practices that Shape the Experience of Indigenous People Living with Dementia and their Caregivers

Only two papers commented on the community, cultural and spiritual practices that shape the experience of Indigenous people living with dementia and their caregivers. (Rosenberg et al., 2009; Ward et al., 2023). However, the theme is crucial as it provides some understanding about where and why Indigenous people have different coping mechanisms (to be discussed in the next theme section) that can help mitigate their stress.

Rosenberg et al. (2009) report that almost 12% of the Indigenous population is over 55, and the living arrangements of older Indigenous people are different from those of non-Indigenous people. Indeed, many Indigenous peoples live in either rural or remote areas of the country. However, overall, few Indigenous women ever live alone. Instead, women live with their partner, but many are dependent on younger family members who live with them and can assist with their care. The authors believe this is indicative of a system of informal caregiving that is touted as "authentically Native and the main culturally appropriate way to fulfill the need for care" (Buchignani & Armstrong, 1999, as cited in Rosenberg et al., 2009, p. 18).

After meeting with Indigenous representatives to design a research study that would provide insights about family caregiving, Ward et al. (2023) interviewed six family caregivers, along with fourteen community healthcare providers and six community healthcare leaders from two Treaty Six Cree Nations in Alberta. The 2021

Census found that the Samson Cree Nation and Enoch Cree Nation have a total of 5077 people living on the two reserves and primarily speak the Plains Cree language. Overall, caregiving was described as part of the culture. Caregiving and receiving care were seen as roles provided by the Creator to fulfill a purpose at a particular time in their lives.

Furthermore, Ward et al. (2023) explain that family included the immediate family of parents and grandparents, children and siblings, aunts and uncles, but extended to cousins and other kin, as well as all the people living in the community. The statement "we are all intertwined" was part of the Cree identity that recognized "we just do it because it's part of our nature." However, as interviews progressed, there was an acknowledgement that being a family caregiver often had only one person as the primary caregiver and that person usually felt they were not receiving support from the others in their family, or their community.

The Coping Mechanisms that help Indigenous People Living with Dementia and their Caregivers Manage Stress

In the final theme, six studies (Crosato et al., 2007; Rosenberg et al., 2009; Beatty & Weber-Beeds, 2013; Bourassa et al., 2021; Gaspard et al., 2021; Alcock, 2019) introduced coping mechanisms that can help Indigenous people living with dementia and their caregivers manage stress. These studies are representative of participatory research being conducted with the Indigenous people it intends to serve.

Crosato et al. (2007) believe that healthcare systems in non-Indigenous communities have forced caregiving onto female family caregivers. However, the interconnectedness of Indigenous families and their communities was seen as essential to the Indigenous women interviewed so they could provide more effective care. Moreover,

if the family supported the healers, the experiences of providing care became a value. For Indigenous women living off-reserve, outside of their Indigenous communities, the lack of family support would lead to social isolation and caregiver stress.

Alcock (2019) used storytelling by Anishinaabe and Métis women to provide their perspectives on caring for their husbands who were living with dementia, while examining the barriers they encountered with the Canadian healthcare system. The women offered stories of resiliency and strength and spoke of the importance of intergenerational kinship and family while caregiving with minimal community services support. In this study, Indigenous women's caregiving experiences occurred while caring for a male family member who was either a husband, a father or a grandfather. The lived experiences of the caregivers were noted to be both valuable and essential for bringing about changes in a healthcare system that needs to break down barriers and introduce self-determination and cultural safety in much-needed resources and support.

Some projects have sought to improve the education being provided to Indigenous people living with dementia and their caregivers to reduce caregiver stress. Gaspard et al. (2021) explained how the Gitxsan Health Society, in collaboration with the First Nations Health Authority in British Columbia, endeavoured to improve the nursing staff's knowledge, attitude and skills in providing care to people living with dementia, their family caregivers and several communities of the Gitxsan Nation. The project used a Two-Eyed Seeing framework, and the research used a participatory action research model, ensuring the Gitxsan people were included in the whole research process. The study included interviews and learning circles with people living with dementia,

caregivers, nurses and any community members interested in information about dementia. Then, there were grounding cultural workshops to enhance cultural learning and sharing circles in the community to evaluate successes and failures.

Although it was challenging to assess the experiences of people living with dementia, Gaspard et al. (2021) determined, through a final sharing circle, that community members, people living with dementia, and their caregivers expressed a desire for ongoing information. Community and family members also wanted to change the belief that a person had "gone nuts" to a more tolerant understanding of the behaviours associated with dementia, so that people living with earlier stages of dementia might reach out to others for support. Furthermore, a need for a day centre for caregiver respite was deemed a required action.

In Canada, many Indigenous peoples are strongly against the institutionalization of their Indigenous seniors, as they believe the care is limited. Indigenous peoples want to be caregivers for their seniors within their home communities. Additionally, Indigenous people are often unwilling to adopt Western-style medicine as they perceive it to be threatening the traditional roles of older Indigenous peoples within their communities. They also believe that traditional ways of knowing are devalued outside of their communities (Rosenberg et al., 2009).

Despite being strong and resilient, Indigenous caregivers sometimes require respite from being a caregiver. Bourassa et al. (2021) recognized a lack of culturally appropriate resources and training for Indigenous caregivers of people living with dementia. Their research project aimed to develop an Indigenous Respite Care Toolkit

despite the lack of effective research on respite care for Indigenous peoples. Indigenous communities also lack the financial resources for training or hiring respite workers on-reserve that might promote aging in place without leaving all the responsibility to informal caregivers. In contrast, non-Indigenous caregivers have better access to respite care and other support. Key components analyzed for the Toolkit included adult daycare and related services, in-home care, respite services, and overnight respite care.

The Indigenous Respite Care Toolkit was developed in Saskatchewan, but with the hopes that other Indigenous communities could create a local version. However, the cost of establishing these services would vary across the different regions and provinces in Canada. Also, the research suggested that training modules to assist and guide Indigenous caregivers in dealing with the various stages of dementia would also require financial resources, with local collaboration and consultation. An important theme recognized by Bourassa et al. (2021) was that caregivers wanted traditional spiritual practices to be included in the Toolkit, as well as specific supports that could help a caregiver provide care to the person living with dementia. Culturally competent information about dementia and its stages, and strategies for continuing to offer care were deemed necessary, especially if provided in the local language.

Beatty & Weber-Beeds (2013) discussed how the Peter Ballantyne Cree Nation (PBCN) Health Services have approached respite care as part of a shared caregiving approach in northeastern Saskatchewan. The PBCN has, since 1995, had the goal of achieving self-determination while building healthier communities. As many of the PBCN seniors needed to leave their home reserves due to inadequate services, the PBCN

had a series of interviews with the seniors to determine the strengths and weaknesses of the health programs they were offering. The study determined that the four community programs they were studying encouraged community involvement, and all were promoting traditional activities like storytelling. There were also social activities to reduce isolation and encourage mobility.

However, Beatty & Weber-Beeds (2013) explain how access to resources was challenging with a lack of skilled nurses and home care aides. Respite care was also lacking, and the coordination between various health authorities was problematic. There were areas within the control of the PBCN requiring improved policy, and jurisdictional issues often required higher-level political and other actions to achieve greater improvement in both the quality of life and care of senior Indigenous people. More importantly, there was a recognition that if resource gaps could be filled, there might be a chance to decrease the number of seniors being forced into cities to receive care.

Finally, Alcock (2019) states that in addition to federal government issues on-reserve, there are issues off-reserve because those Indigenous peoples require provincial government funding. Therefore, access to services and benefits varies by geographical location. Individual eligibility is often determined by the jurisdictional boundaries established under the Indian Act, which excludes the Métis. Therefore, in addressing the lack of services, local healthcare providers must understand the colonized policy structures that impact Indigenous peoples living with dementia and their caregivers.

Discussion/Conclusion

This MRP has explored the research on people living with dementia and their caregivers within the Indigenous populations (First Nations, Inuit, and Métis) in the geographical regions of Canada. A Critical Disability Studies framework was used to examine the intersections of dementia (disability), identity, culture, and systemic barriers in dementia caregiving.

The statement that "colonial policies create historical traumas" (Racine et al., 2022) helps us to understand how health and social inequities have plagued Indigenous peoples. Historical trauma has likely contributed to the recent surge of Indigenous people developing dementia in Canada, even if there is a debate about whether all Indigenous peoples have experienced similar amounts of historical trauma. Canadian policies that supported and enforced the relocation of Indigenous peoples to reserves, the criminalization of traditional healing practices or ceremonies, or the residential schools that removed children from their communities, all represent racist examples of historical trauma that continues to affect Indigenous peoples. Racism results from historical traumas, and racism is rampant within the Canadian healthcare system, which affects those Indigenous people living with dementia and their caregivers.

To truly understand "historical trauma" in Canada, people need to realize that with legislation like the Indian Act (1876), the government's official policy of assimilation led to the development of residential schools, where children were removed from their communities and prohibited from practicing their traditional customs or using their language. The residential schools have impacted generations of Indigenous peoples

since the 1870s, as those children were psychologically intimidated, neglected, or physically, sexually and spiritually abused by their repressors, who were often operated by Christian churches involved in missionary work in North America (Woods, 2013; MacDonald & Steenbeek, 2015; Wilk et al., 2017). MacDonald & Steenbeek (2015) reference Amnesty International reports how the harsh punishments children endured, including being denied food or being chained to their beds. Therefore, children might run away, steal food, or commit suicide to escape their inhuman living conditions.

Although the last residential schools closed in 1996, it is estimated that more than 150,000 Indigenous children were affected by residential schools. Today, Indigenous peoples continue to be impacted by generational family violence, addictions to alcohol and drugs, and sexual and physical abuse (Woods, 2013; MacDonald & Steenbeek, 2015; Wilk et al., 2017). According to Wilk et al. (2017), not only has European colonization and assimilation physically and psychologically harmed the health and well-being of Indigenous peoples, but there is disproportional harm to the health of Indigenous communities compared to non-Indigenous communities. Most of these health disparities circle back to the government policies used to assimilate Indigenous people into the Euro-Canadian lifestyle.

Wilk et al. (2017) describe how the concept of "historical trauma" continues to impact Indigenous communities. Although many of the children who attended residential schools are now deceased, the transgenerational effects on their families have included the collapse of societies and families, increased suicide and mortality rates, health problems, substance abuse, and criminality. The reparation of the effects of the

residential school system for Indigenous peoples in Canada was deemed instrumental in the development of 94 “calls to action” by the Truth and Reconciliation Commission of Canada (Truth and Reconciliation Commission of Canada, 2012; Truth and Reconciliation Commission of Canada, 2015).

MacDonald & Steenbeek (2015) offer definitions of colonization within Canada that resulted in the loss of Indigenous culture, language, medicine, and ways of knowing. They refer to Freire’s description of colonization as exploitation of one nation by another, or a “cultural invasion” that is meant to “inhibit the creativity of the invaded by curbing their expression.” Furthermore, colonizers used the assimilation of Indigenous peoples to force upon them government policies, education systems and European societal norms to remove any trace of Indigenous peoples’ customs, language, traditional practices (including health), education and values.

Moreover, Alcock (2019) states that, due to the historical trauma caused by colonization, many Indigenous people are isolated from receiving any non-Indigenous assistance. Indigenous communities are fearful of being dependent on funding and governance from the federal government, and this is likely a cause of the minimal access or a complete lack of dementia services available. As Indigenous peoples seek self-determination, there is the ongoing paradox of dependence on government funding.

Horrill et al. (2018) explain how access to healthcare is recognized as a social determinant of health that is impacted by many barriers to care, despite the equity principle that care should be distributed based on need. Healthcare access for Indigenous people in Canada has not been equitable. Applying a postcolonial perspective can lead to

a better understanding of healthcare access for Indigenous Peoples. Postcolonial theory requires a recognition that providing healthcare is primarily a social relationship and is not simply the provision of available and deliverable healthcare services. Therefore, Horrill et al. (2018) state that to improve healthcare access for Indigenous peoples, healthcare will need to be conceptualized as a social relationship in social spaces that are safe, socially inviting and acceptable. Applying a decolonization perspective will require a focus on the historical influences that have caused barriers to access.

A study by Mitchell et al. (2019) explains how the social determinants of health for Indigenous people in Canada continue to be affected by colonialism despite Indigenous peoples' resistance to colonial interference and aggression. Documented inequalities in mortality and morbidity rates for Indigenous peoples, notably the reduced life expectancy, higher infant mortality and a greater disease burden exist. However, health disparities are seldom researched based on political, historical, and cultural determinants. Improving the health and well-being of Indigenous peoples requires an understanding of the complex and extensive historical and political context of colonial trauma. Furthermore, researchers and policymakers must understand how colonial trauma has affected generations of Indigenous peoples in continuous, compounded and cumulative ways.

Interestingly, Elias et al. (2012) suggest that historical trauma theories can explain suicide amongst Indigenous people. These theories often compare the intergenerational trauma seen in holocaust survivors to the assimilation and genocide of Indigenous peoples that is a result of government policies. They propose that in Canada, the

residential school system started a hundred-year cycle of trauma. These children not only lost their traditions, culture and language, but they were disadvantaged by their lack of family bonding or parenting skills. Sadly, their parents could not have the experience of nurturing or becoming caregivers. Residential school survivors did not only report substance abuse, violence or sexual abuse, but developed many of the feelings of hopelessness and isolation leading to suicidal behaviours. Regrettably, trauma has been transmitted to at least four generations of Indigenous residential school survivors in Canada (Elias et al., 2012).

Offering a slightly divergent opinion, Bourassa et al. (2015) provide examples of resiliency and strength that came from residential school experiences. Some Indigenous people appeared not only to survive but thrive despite the colonization of generations of their families. Their study determined that some Indigenous people were able to heal because of a strong community and family connections, or through participation in traditional healing practices. Although many Indigenous peoples would not ascribe their experiences in residential schools as ones where they thrived, this opinion is in keeping with much of the research that has been reviewed in this MRP, which highlights the importance of community and family connections in caregiving.

This literature review on Indigenous caregivers of people living with dementia has provided a summary of the research available on the topic. Many examples have been provided of how caregiver stress can be mitigated by understanding the colonial trauma that Indigenous peoples have been subjected to (through postcolonial and decolonization theories and other Indigenous Ways of Knowing), and then, through their participation in

developing and conducting research, care models that support them can be created. However, one of the research questions for this MRP was to explore what research and literature gaps remain on Indigenous people living with dementia and their caregivers.

In the future, researchers (and participant co-researchers) might consider research that includes or highlights the voices of Indigenous men who are caregivers to people living with dementia, which is lacking. Furthermore, geographically, there was a lack of studies looking at those First Nations, Inuit and Métis peoples in the Eastern provinces of Canada (Newfoundland and Labrador, Prince Edward Island, Nova Scotia and New Brunswick) and from the northern regions of Canada (Yukon, Northwest Territories, and Nunavut). This MRP did not look at French studies from Quebec, so no comment on their availability is being made. There is undoubtedly good representation from Ontario and the Western provinces. The voices of Inuit people are lacking in all regions of Canada.

Furthermore, there were no studies that addressed how Indigenous communities provide caregiving to those people living with dementia differently. Studies were invested in demonstrating the use of Indigenous Ways of Knowing, including Two-Eyed Seeing approaches, in their development and conduct of research projects. Hopefully, since most of this research is from the last five years, further studies will be developed to explore the effectiveness of previously studied interventions.

In closing, I believe that community organizations, policymakers, and healthcare providers should continue to learn about cultural safety and be prepared to participate in the development of culturally informed research with Indigenous peoples. I would recommend that they too, at the very least, read 2015 reports, including *The Truth and*

Reconciliation Commission of Canada and, *Canada's Residential Schools*, as well as *Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls (2019)* so that they can begin to understand the impact of colonial trauma on the Indigenous peoples in Canada.

Epilogue

After writing this MRP, I was able to spend some time reflecting on the literature that I had been immersed in for so many months. I had envisioned a paper that might compare the literature of non-Indigenous and Indigenous people providing care to those people living with dementia. However, in retrospect, I was going to write a literature review with a Western or Eurocentric research perspective. I was looking for the statistics that would prove that Indigenous caregivers had a more negative experience than non-Indigenous caregivers.

Imagine my surprise as I was confronted by my own biases and realized that the concepts of Two-Eyed Seeing applied to me and my research. As I spent time thinking about my MRP topic and conducted very early literature searches, there were only a few papers, fewer than ten, written about Indigenous people with dementia and their caregivers. However, in the last two years, several new research papers have been published, and those papers have used different approaches. These papers were enthusiastically informing the reader about decolonization and postcolonial theory. Many research projects were utilizing a Two-Eyed Seeing approach in the development and dissemination of their research.

Therefore, I am fortunately unable to offer a wealth of knowledge in a homogeneous format of tables and figures about the experience of Indigenous people living with dementia and their caregivers. Instead, my MRP has provided pockets of knowledge about specific Indigenous communities. I hope that the research will provide much-needed information to those communities while offering sustainable change because of that knowledge.

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