Can We Achieve Culturally Safe Cancer Care: A Critical Thematic Analysis of First Nation Cancer Care Experience

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Abstract

Despite significant advances in cancer prevention, detection, and treatment, Indigenous Canadians continue to experience markedly poorer health outcomes and lower survival rates from cancer and cancer-related illnesses compared to non-Indigenous Canadians. These disparities stem from systemic failures within the healthcare system to meet the unique needs of Indigenous patients and their families, resulting in deep mistrust toward the Western biomedical model of care. In recent years, the concept of cultural safety has emerged within the nursing profession as the dominant model for the delivery of culturally appropriate and sensitive care that helps to mitigate the effects of discrimination, stigma, and marginalization in healthcare contexts. This study, conducted in the Algonquins of Pikwakanagan First Nation community, examines community members' experiences within the cancer care system and explores strategies for achieving culturally safe cancer care. Using secondary analysis of qualitative data collected through sharing circles, focus groups, and interviews with cancer survivors, family members, and healthcare providers, the study investigates how First Nations people navigate cancer care. Guided by a critical disability theoretical framework, the analysis interrogates the intersections of power, ableism, colonialism, and neoliberalism in shaping health outcomes. Findings reveal the harmful consequences of a biomedical system where treatment options are limited, and care is accessible only outside the community. Recommendations emphasize the urgent need for a new dimension of care that respects and integrates Indigenous knowledge systems.

Keywords: Indigenous, First Nation, Cancer Care, Cultural Safety, Nursing

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This thesis is dedicated to the Algonquins of Pikwakanagan First Nation people and their families who are living through cancer. A heartfelt thank you for welcoming me into your home and sharing your stories. Your courage and support for your community is inspiring. Living through cancer is destabilizing, isolating, and debilitating. It is my hope that together we can create a cancer care system that champions Indigenous ways of knowing, being and living.

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Chapter 1: Introduction

Background

Indigenous peoples are the original habitants of the North American continent, with a rich history spanning back thousands of years before the first Europeans first stepped foot on North American soil. In Canada, there are three recognizable subgroups of Indigenous people: First Nations, Métis, and Inuit, with over 1.8 million Canadians identifying as Indigenous. Within these three recognized groups exist hundreds of culturally distinct communities, bands, and tribes with unique languages and beliefs (Statistics Canada, 2021). First Nations make up the largest group of Indigenous people, with over one million individuals self- identifying as First Nations including 600 culturally distinct bands and over 70 unique languages (Mazereeuw et al., 2018; Statistics Canada, 2021).

The first contact of European settlers with Canadas first people resulted in a steady decline of the health and wellbeing of Indigenous people as they were introduced to biological and social challenges that threatened their wellbeing (Schill & Caxaj, 2019). The health of Indigenous peoples is intimately and inextricably linked to the societal, historical, and political contexts in which they live (Gifford et al., 2019a; Segolov & Garvey, 2020). Despite significant advances in cancer prevention, detection, and treatment in the past several decades, Indigenous people continue to experience markedly poorer health outcomes and lower survival rates compared to non-Indigenous Canadians (Cancer Care Ontario [CCO], 2023; Christie et al., 2021; Cole et al., 2021; Dasgupta et al., 2017; Gifford et al, 2019a). For example, First Nations and Métis patients face significantly higher levels of pain, depression, anxiety, and shortness of breath during treatment compared to Caucasian patients (Bodnarchuk et al., 2014). Canadian data demonstrates that Indigenous people have markedly lower participation in cancer screening programs including mammography, and lower participation in cancer treatment regimes and surveillance, leading to poorer health outcomes and higher mortality compared to non-Indigenous Canadians (Bryant et al., 2021; CCO, 2023; Enuaraq et al., 2021). Disparities in cancer incidence and survival between Indigenous and non-Indigenous people in developed countries are large, and continue to widen alongside ongoing cost of living challenges, reduced funding for community-based programming, and patchwork approach to healthcare delivery (Horill et al., 2020; Lavoie et al., 2010). This health disparity must be understood in the broader context of violent practices of colonization and acculturation that continue to shape health outcomes for these communities (Gifford et al., 2021; Reading, 2015; Schill & Caxaj, 2019). Indigenous racism is well-documented in the literature and continues to permeate our healthcare system, with a deluge of studies exploring the negative first-hand experiences of Indigenous people's encounters with Western healthcare systems, further deepening the health disparity in this country (Allan & Smylie, 2015; Kitching et al., 2016; Tang and Browne, 2008). There is evidently a demonstrable need for a different approach to health that better fits the needs of Indigenous Canadians.

The British North America Act of 1867 (renamed Constitution Act) formally established the Dominion of Canada and proffered full authority over Indigenous land and peoples to the new Canadian federal government. This newly established federal government subsequently consolidated two pre-existing colonial legislations to establish the Indian Act in 1876. The new Indian Act (1876) further formalized the euro-colonial state's ownership of Indigenous land, restrict Indigenous freedoms, promote forcible assimilation into white society (so-called "enfranchisement"), and forbid Indigenous peoples from expressing or engaging with their culture (Reading, 2015; Royal Commission of Aboriginal Peoples [RCAP], 1996; Truth and

Reconciliation Commission of Canada [TRC], 2015). The Act imposed a reserve system, where status Indians were annexed to certain areas of land through forced relocation (Horill et al., 2019). Many of these reserves are located in remote areas where access to safe drinking water and healthy food is severely restricted (Reading, 2015). Subsequent amendments to the Indian Act gave further authority to the federal government. The 1884 amendment formalized the government's control of schooling and education for Indigenous peoples and established a formalized system of residential schools which were jointly run by Christian and Protestant churches and the federal government (TRC, 2015; RCAP, 1996). The 1920 amendment made attendance at these schools mandatory for all Indigenous children. The first Indigenous residential schools opened at the turn of the twentieth century, and, by 1930, 75% of Indigenous youth had been ripped from their families and forced to live by imperial-settler ideals (Horill et al., 2019). It was in these institutions that Indigenous youth were subjected to horrific acts of physical, sexual, and psychological abuse at the hands of colonial settlers, including nurses who staffed these institutions (Horill et al., 2019; TRC, 2015). Forbidden from seeing their loved ones, speaking their language, or engaging with their culture in any way, many were driven to suicide (Cervin, 2021; Richardson & Boozary, 2021). This complex intergenerational trauma is passed down through generations and continues to exert deleterious effects on Indigenous populations continuing up until present day (Allan & Smylie, 2015; Browne et al., 2016; Gifford et al., 2019a). The last residential school closed its doors in 1995 (TRC, 2015), and since then, marginal efforts have been made to reconcile with the violent acts of colonization and acculturation (Gifford et al., 2019a, 2019b; Health Council of Canada, 2012; Schill & Caxaj, 2019), but the violence is far from over. Widespread infectious disease including tuberculosis in the twentieth century resulted in a weakening of community capacity to provide food and shelter to its members. Infectious disease was then overtime replaced by chronic conditions including cancer (Beben & Muirhead, 2016) The TRC (2015) proposed 93 Calls to Action to address health inequities that have come to define our healthcare system. Notably, the Call to Action #18 and #22 call upon health governments and those within them to acknowledge that the health disparities seen are a direct result of ongoing colonial violence, and take measurable steps to rebuild a more equitable health system:

> #18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.
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> #22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients. (TRC, 2015, p. 2-3)

This has proven to be a very difficult task as healthcare institutions are deeply embedded in the imperialist-colonial biomedical paradigm that emphasises a purely Western conception of health and disease (Beckett et al., 2021). Reckoning with Canada's history of violent historical atrocities against Indigenous people requires honest reflection of the ongoing harms enacted by European colonial regimes, and the ongoing benefits for Euro-Canadian society. It is only through a thorough understanding of these harms and mistakes, that we can begin to dismantle and rebuild a healthcare system that better serve Indigenous communities.

Thesis Objectives and Questions

Nursing as a profession has intimately adopted cultural safety as its primary approach to addressing health equity concerns within Indigenous communities (Brooks-Cleator et al., 2018). However, a critical understanding of cultural safety and the ways it is experienced by First Nations communities, specifically in the cancer care sector, is lacking. This thesis aims to engage in a critical discussion about culturally safe cancer care from a critical disability framework perspective. The guiding questions for this thesis are:

1) How does critical disability theory help better understand the experience of cancer in Indigenous communities?
2) How do community members of Algonquins of Pikwakanagan First Nation view cultural safety in cancer care?

Through meaningful collaboration and ongoing relationship-building with members of the Algonquins of Pikwakanagan community, the thesis aims to engage in a critical discussion about cultural safety and its role in cancer care. This thesis is meant to add to a growing body of knowledge surrounding the critical exploration of the ideologies that underpin our health services, and the experiences of the people who have historically been underserved, oppressed, and ignored within those systems. What it is not meant to do is disparage the important work that is being done by these organizations to confront the health disparities our health systems have caused, but begin to address the systemic issues embedded within them.

Cancer Care Ontario – Guidelines for First Nations Cancer Prevention

Cancer Care Ontario (CCO), the provincial government's principal cancer advisory group, is an organization whose purpose is to provide health care workers, organizations, and policymakers with the most up-to-date information on cancer knowledge (CCO, 2023). The CCO has released a series of guidelines on cancer prevention for First Nations communities, with a heavy emphasis on ‘modifiable risk factors’ for reducing one’s risk of cancer including reducing negative health behaviours such as smoking and heavy alcohol use, avoiding unhealthy foods, and remaining physically active. The guidelines emphasize personal risk factors as the cause of cancer development, and highlight that modifiable risk factors are related to individual life choice (CCO, 2023). Unfortunately, these guidelines for cancer prevention focus on behavioural modification at the individual level and fail to acknowledge the broader societal and institutional systems and structures that perpetuate the conditions which lead to cancer and other chronic diseases in these communities. For example, the guideline on healthy eating instructs First Nations to eat fish with caution because of toxic mercury bioaccumulation (CCO, 2023), failing to acknowledge the broader sociopolitical colonial policies that resulted in the poisoning of a main food source of First Nations people. Moreover, intergenerational trauma experienced by Indigenous people at the hands of colonial settlers as well as the introduction of alcohol during the implementation of colonial regimes can account for the increased consumption of alcohol, most prominently on reserves (Weatherall et al., 2020). The guidelines refer to First Nations women living on reserves as more likely to be ‘binge-drinkers’ than their non-Indigenous counterparts, further perpetuating negative stigma of First Nations women, and suggesting a moral component to achieving good health. See Appendix A for an example of the CCO First Nation guidelines for alcohol consumption and cancer risk. The responsibility of Indigenous people to modify their individual behaviours erases the impact of colonial violence and precludes the possibility of political and institutional change to acknowledge the damage of colonization, and a relinquishing of biomedical and governmental control over Indigenous people’s self-determination.

Researcher Positionality

I am a settler-colonial Euro-Canadian born and raised in Ottawa on unceded Anishinaabe Algonquin territory. Throughout high school and my first undergraduate degree, I learned nothing of Indigenous culture, and nothing of the horrific legacy of violence and colonization inflicted against the Indigenous people, the effects still ongoing today. After being introduced to Indigenous literature, both fiction and non-fiction, I began to uncover the dark side of Canadian history that had been hidden from us throughout my education. The year I began my nursing education was the same year the federal government released the TRCC's 94 Calls to Action to address the ongoing systemic violence inflicted on Indigenous people. Number #24 called on medical and nursing schools to provide education on Aboriginal health issues, including the legacy of residential schools (TRC, 2015). Unsurprisingly, I immediately gravitated toward Indigenous health research and health equity initiatives throughout my undergraduate degree, and upon graduating, assisted in implementing an expanded curriculum on Indigenous health to first-year nursing students. I graduated and began working at a busy hospital in the year 2020, the same year the COVID-19 pandemic laid bare many of the systemic injustices in our healthcare system that caused marginalized and disenfranchised communities to be disproportionately affected and afflicted by certain health conditions. This pushed me to pursue a Master's education in nursing to better understand how the nursing profession can strengthen health equity and better serve marginalized communities.

That same year, I was diagnosed with breast cancer, a late effect of the chemotherapy and radiation I received some years prior to treat advanced Stage IV lymphoma. I have been in and out of the cancer system for twenty years, dealing with multiple life-threatening relapses and side-effects of my treatment. Navigating the cancer care system is difficult, and I continue to struggle with keeping up appointments, managing the side effects of treatment, and making complex treatment decisions at highly stressful times. I often felt dehumanized, depersonalized, and powerless in a system focused on biomedical markers of disease.

What I began to learn at the beginning of my Master's studies is how profoundly embedded the nursing profession is in not only the Western biomedical system, but in the historical legacy of residential schools and ongoing systemic violence at the hands of the Catholic Church. Nurses were some of the first people to staff Indigenous residential schools and played an active role in the deluge of horrific acts preformed upon children including medical experimentation, and physical and sexual abuse. As more stories and first-hand accounts of residential school survivors are brought forth, we are only now learning the extent of the horrors that occurred at these institutions. I recognize that Western research methods employed by the nursing profession are grounded in an empirical, positivist understanding of health and disease, and have directly contributed to the ongoing colonial harms inflicted upon Indigenous communities, perpetuating a healthcare system built upon racist, colonial ideals. Through employing a reflexive, subjective, and ongoing approach to content analysis, I aim to champion and amplify Indigenous voices to better understand their experience with cancer.

As the author of this thesis, it is of the utmost importance to acknowledge my identity as a non-Indigenous Euro-Canadian settler employed as a registered nurse in tertiary care setting underpinned by a biomedical understanding of health and disease. As research assistant with the university, I work closely with Indigenous communities and seek to understand and share their viewpoint, however it is impossible for me to fully dislodge myself from a deep-rooted paradigm of Western thought.

Ethical Considerations

Due to the deep undercurrents of abuse of trust between settler and Indigenous people, there is a hesitancy of sharing traditional knowledge, beliefs, and worldviews for the fear that it will be misconstrued, misappropriated and misrepresented in Western frameworks of knowledge development (Kovach, 2021). Indigenous elders are considered Keepers of Knowledge, and knowledge is often disseminated through stories, dances, ceremonies, and art. Western methods of data collection, interpretation, and dissemination often fall short in capturing the true essence of Indigenous knowledge, and therefore a full integration of Indigenous-based methodology is required. Furthermore, knowledge of Indigenous ways of living should not become the possession of Western researchers and should not be self-serving of non-Indigenous agendas. The OCAP® principles (Ownership, Control, Access, and Possession) are strong guiding principles for the collection, interpretation, and application of indigenous research projects (First Nations Information and Governance Center [FNIGC], 2018; Kovach, 2021). Firstly, the principle of ownership states that a community owns cultural knowledge in the same way that an individual owns personal information, therefore the community's consent is required to use said knowledge. The principle of control states that Indigenous people have a right to control research methods, frameworks, and data management and dissemination. Next, access refers to the ability for Indigenous people to freely retrieve and examine research data pertaining to their communities. Lastly, possession refers to the actual possession of data, and asserts that research data does not belong to the researcher, but remains in the possession of the research participants (FNIGC, 2018; Kovach, 2021). The OCAP principles underpin every step of the research process throughout this project, including the ongoing dissemination of findings to the community.

Thesis Outline

This thesis consists of six chapters:

1. Chapter one is an introduction to my research topic including background, research questions, ethics, and researcher positionality
2. Chapter two consists of the literature review focusing on the cancer burden in First Nations communities, as well as cultural safety and cancer care in Indigenous communities globally. In addition, this chapter expands on the inter-related terms of cultural competence, cultural sensitivity, and cultural awareness, and their relation to the concept of cultural safety within the nursing profession.
3. Chapter three introduces the chosen theoretical framework that guides this study. Critical disability theory is the overarching paradigm that frames my research questions, with a particular focus on the concepts of debility (Puar, 2017) and inclusionism (Mitchell & Snyder, 2015).
4. Chapter four outlines the research design and methodology, including a brief overview of the primary study on which this secondary analysis is based, the participations, and data collection methods. I then introduce Reflexive Thematic Analysis (Braun & Clarke, 2015) as my chosen methodological approach to data analysis and thematic development. Finally, I discuss data storage, and ethical considerations throughout the research process.
5. Chapter five describes the results of the Reflexive Thematic Analysis
6. Chapter six presents the integrated discussion of the results through the lens of critical disability theory. The chapter is concluded by outlining nursing implications in the

four domains of practice, policy, research, and education, as well as the study strengths, limitations, and areas for future research.

I have chosen to conduct a secondary analysis from data collected from a previous study with the Algonquins of Pikwakanagan First Nation's community. It must be acknowledged that research with Indigenous communities has been too-often conducted by settler-colonial researchers, which can result in the misappropriation of Indigenous experiences and knowledge systems. I continue to reflect on my positionality throughout the entirety of this project and strive to maintain ongoing relationships with the members of the Algonquins of Pikwakanagan First Nation community to ensure my findings are reflective of their experiences. It is my hope that this study will contribute to a growing body of knowledge that aims to reduce the health disparities between Indigenous and non-Indigenous people and help gain a deeper understanding of the experience of First Nations people in the cancer care system.

Chapter 2: Review of the Literature

In this chapter, I aim to synthesize the current literature surrounding culturally safe cancer care within Indigenous communities. After describing my search strategy, I explore the meaning of cancer to Indigenous people, as well as their experiences of cancer care along the cancer care continuum. I then describe cultural safety and how it is applied to both cancer care and the nursing profession. To better understand the concept of cultural safety within the nursing profession as it relates to cancer care, I divide the literature into four sections: training and education, navigation and role integration, and access. Finally, I discuss the conceptual ambiguity of cultural safety and the biomedical constraints in applying it in nursing practice.

Search Strategy

This study's literature search centered around key concepts of cultural safety, Indigenous health and wellbeing, and cancer care in Indigenous communities. Academic literature was gathered through PubMed, EBSCOhost, Cumulative Index to Nursing and Allied Health Literature (CINAHL). In addition, grey literature including Government of Canada, provincial health websites and news articles were accessed to establish a broad understanding of the state response to cancer surveillance and control.

Search terms and key words included "Indigenous" OR "First Nation", AND "cancer", "cancer care", "cultural safety", "culturally safe" AND "cancer care". Search terms were exploded to include related terms such as "malignancy", and "neoplasm". Boolean operators were used strategically to narrow the search. To obtain a broader understanding of approaches to cancer care with Indigenous communities, a global approach was used, focusing on areas with a history of colonization and health disparities. For example, much of the research surrounding cultural safety and cancer care has emerged out of Australia and New Zealand, with a focus on

Torres Strait Islander and Māori populations. Unsurprisingly, their findings extend to other countries that have similar histories of colonization. The inclusion criteria encompassed systematic reviews, primary research articles, and both qualitative and quantitative research. Articles must have been peer-reviewed, in English, and published within the last ten years. The reference management software Mendelay was used to organize the selected literature for review.

The preliminary search of the databases yielded a total of 5,460 articles. After the removal of duplicates, the application of screening criteria, and abstract review, 36 articles were selected for full review. See Appendix B for Inclusion/exclusion criteria, Appendix C for search strategy, and Appendix D for the PRISMA diagram outlining the search results.

First Nations and Cancer Care

First Nation people of Canada have a disproportionately higher risk, incidence, and mortality from colorectal, kidney, cervical, and liver cancers, and a lower incidence of breast, brain, uterine, and bladder cancers compared to non-First Nations populations (Assembly of First Nations, 2017; Health Counsil of Canada, 2005; Mazareeuw et al., 2018; Thomas et al., 2023). Cancer is now the leading cause of death in First Nations communities (Canadian Partnership Against Cancer [CPAC], 2013; Horill et el., 2020). Government policies rooted in colonialism add complexities for First Nations people, specifically those living on reserve when accessing cancer care, as fiduciary conflicts between provincial and federal jurisdictions of care are often confusing and contradictory (Beben & Muirhead, 2016). This jurisdictional division of responsibilities has effectively created a separate and parallel cancer care system for First Nations communities living on reserve (Horill et al., 2018, 2019; Lavoie et al., 2010). For example, an article by Lavoie et al., (2015) states that delays in receiving a cancer diagnosis can be linked to “a federal transportation policy that will not subsidize transportation for preventative and diagnosis purposes” (p.7). Cancer stage at diagnosis is an important predictor of treatment options, mortality, and quality of life in survivorship (CPAC, 2013). First Nations peoples are more likely to be diagnosed with late-stage disease than non-First Nations populations, which can result in more invasive and costly treatment options (Decker et al., 2016: Horill et al., 2019, 2020; Thomas et al., 2023). Cancer diagnosis often begins in the primary care setting, however difficulties accessing primary care for First Nations communities is well-documented and often requires travel outside of the community (CPAC, 2013; Horill et al., 2020; Lavoie et al., 2015; 2016b). In a study exploring First Nation’s women’s experience in the cancer care system, many reported it felt as though they had fallen through the cracks (Poudrier & Mac-Lean, 2009). Several studies demonstrate that spirituality, namely connection with nature, family, culture, and communities were key factors in healing throughout the cancer care continuum for First Nations populations (Cavanagh et al., 2016; Gifford et al., 2020; Thomas et al., 2023).

Cultural Safety and its Role in Nursing

Since the 2015 release of the TRC’s 94 Calls to Action, the concept of cultural safety and culturally safe care has gained momentum in nursing pedagogy as a framework for addressing the health disparities that exist between Indigenous and non-Indigenous populations in Canada (Horill et al., 2022; Webb et al, 2023), and mitigate the ongoing effects of racism, discrimination, and marginalization in healthcare contexts (TRC, 2015). Health care institutions are increasingly promoting cultural safety education initiatives and attempting to integrating Indigenous knowledge and ways of being and healing into cancer care systems across Canada (Beckett et al., 2021; Brooks-Cleator et al., 2016; Gifford et al., 2022).

The concept of cultural safety has gained popularity within the nursing profession as a model for the delivery of culturally appropriate care that helps to mitigate the effects of discrimination, stigma, and marginalization in healthcare contexts (Allan & Smylie, 2015; Schill & Caxaj, 2019; Tremblay et al., 2023). The concept as it applies to nursing care and patient-client relationships has been increasingly integrated into formal nursing curriculums in effort to address the inherent power imbalances seen in Western healthcare systems (Brooks-Cleator et al., 2018; Rand et al., 2023). Since the formal undertaking of reconciliation efforts at the federal level in 2015 and the creation of the Truth and Reconciliation Commission (TRC) Calls to Action, healthcare fields have had a galvanized interest in producing research concerning culturally safe approaches to a care within the Indigenous populations.

Cultural safety as a concept in healthcare was first theorized by Irihapeti Ramsden, a nurse of Indigenous Māori Identity in New Zealand in the early 1980s (Gerlash, 2012; Parisa et al., 2016; Ramsden, 1992; Schill & Caxaj, 2019). She theorized culture as a fundamental human right, with the power to influence health outcomes as well as enhance health promotion. Central to her definition of cultural safety is the beliefs that the significant health disparities seen in Indigenous peoples were a direct outcome of centuries of colonial violence that perpetuated cycles of poverty and ill health (Gerlash, 2012; Ramsden, 1992; Tremblay et al., 2023). Cultural safety locates the health of Indigenous people within the context of colonial violence and aims to unveil the deeply rooted and largely subconscious assumptions of power that are embedded in Western healthcare institutions and disciplines (Gerlash, 2012; Ramsden, 1992). Although originally pertaining to Māori health, by the mid-1990s the concept of cultural safety encompassed a global approach to healthcare, including all patients who differed from their healthcare providers in terms of culture, race, gender, sexual orientation, socioeconomic class, and religious or spiritual beliefs (Gerlash, 2012). Building on concepts such as cultural awareness, cultural humility, and cultural competence, cultural safety takes into account the power dynamics at play in the larger sociopolitical context that cause certain cultural groups to be systemically ignored (Schill & Caxaj, 2019). Australian Indigenous nurse Robyn Williams (1999) build upon Ramsden's initial conception of the term and defined cultural safety as,

> An environment that is safe for people: where there is no assault, challenge, or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning, living and working together with dignity and truly listening. (Williams, 1990, p.2)

Cultural safety is more that cross cultural awareness and requires a deep understanding of the pervasive and ongoing traumatic effects caused by government policies and systemic inequalities (Enuaraq et al., 2021; Gifford et al., 2019a; Horill et al., 2020; Keyawosh et al., 2015). In addition, cultural safety within healthcare encompasses a self-awareness of the clinician's own culture, values, and beliefs, and how they interact with larger socio-political power dynamics that shape healthcare services (Schill & Caxaj, 2019). Moreover, cultural safety requires an appreciation of the person as a whole and a recognition that people are connected intellectually, spiritually, and emotionally to others and to the land (Christie et al., 2021). People who experience culturally safe healthcare are more likely to access care earlier, feel more in control while receiving care, and return for follow-up care and surveillance (Rand et al., 2019). Cultural safety comes to fruition at the frontlines of healthcare and is embedded in the interactions between nurses and doctors, and those to which they are providing care (Greenwood et al., 2017). As stated in Papps and Ramsden (1996):

> Cultural safety places an obligation on the nurse or midwife to provide care within the framework of recognizing and respecting the difference of any individual. It is consumers or patients who decide whether they feel safe with the

> care that has been given...it empowers the users of the service to express degrees of felt risk or safety. (p. 494)

Conceptual Ambiguity

It is crucial to distinguish the term cultural safety from the related terms of cultural awareness (acknowledging the similarities and differences among cultures), cultural competence (working effectively with those with cultural differences), and cultural sensitivity (listening and learning about a new culture without judgement). Cultural safety is distinct from these related terms in the sense that it requires a politicized understanding of health and the health systems that enact power onto individual health outcomes. Cultural safety, as opposed to awareness, competence, and sensitivity, requires a radical paradigm shift from an emphasis on interactions between patients and providers, to a broader understanding that health is determined by power, privilege, and bias (Tremblay et al., 2023). In a scoping review of culturally safe approaches to Indigenous palliative care in Canada, Schill and Caxaj (2019) argue that the steps that organizations are taking to incorporate cultural safety into their systems more accurately resemble superficial practices of cultural awareness, sensitivity, and competence. Without a broader commitment by organizations to address the pervasive effects of colonization and the institutional racism that continues to negatively influence health outcomes, any efforts to achieve cultural safety are downgraded to at best encompass cultural competence (Schill & Caxaj, 2019). Culturally safe practices have the potential to lead to profound organizational change and require a deep and genuine commitment to improving the political factors that shape care dynamics (Schill & Caxaj, 2019).

In Canada, the concept of Equity-Oriented Healthcare (EOHC) is useful in analyzing and exploring culturally safe care in the cancer sector. According to the Canadian Partnership

Against Cancer (CPAC), equity is identified as one of its key strategic themes for 2017-2022, pledging to address racism, discrimination and stigma through healthcare provider education and training. The Ontario Cancer Plan identifies equity as one of its six overarching themes, claiming that people should not be disadvantaged for who they are, where they live, or what resources they have (CCO, 2023). However, these organization often fail to address how exactly they plan to address issues of racism or discrimination in cancer care beyond direct healthcare provider training. EOHC as a concept aims to lessen the impact of structural inequities and social determinants of health by exploring the "…frequent mismatches between dominant approaches to care and the needs of people who are most affected by health inequities" (Horill et al. 2022b, p. 188).

Indigenous People's Experience of Cancer and Cancer Care

Cancer care systems rely heavily on deeply engrained biomedical knowledge systems with rigid paternalistic ideas and strict protocol-based standardized care (Horill et al., 2022). Biomedical ways of knowing are rooted in positivism and empiricism, emphasizing prediction, control, and reductionism in the creation of knowledge (Gifford et al., 2021; Horill et al., 2022; Lethborg et al., 2022), often ignoring the larger holistic picture of health and disease. Cancer treatment is typically delivered in tertiary care centers in large urban areas, creating problems of access for those living in rural settings and mirroring colonial issues of displacement and acculturation (Gifford et al, 2021; Horrill et al., 2018, 2019; Lavoie et al., 2015). Patients are often required to travel long distances and be separated from their families, communities, and culture for the duration of their treatment (Enuaraq et al., 2022; Kewayosh et al, 2015). Moreover, there is a documented lack of palliative care services for Indigenous communities that incorporate culturally-relevant end-of-life practices surrounding death and dying (Galloway et al., 2020; Horill et al., 2020).

It is important to note that Indigenous cultures have a unique perspective on cancer and its disease process (Christie et al., 2021; Kolandooz et al., 2014). However, First Nations peoples' conception of cancer, illness, and healing remains poorly represented in the literature. The focus of this section is to review the limited literature on the experience of cancer as a disease in Indigenous communities. Not surprisingly, qualitative studies on the beliefs surrounding cancer in Indigenous communities are largely lacking, with one scoping review identifying only five studies exploring Indigenous cultural beliefs and perceptions about the disease (Shahid & Thompson, 2009). In this review, cancer was viewed by Indigenous people as being a frightening disease, a death sentence likely due to the fact that many Indigenous people are diagnosed at later stages of the disease process. Cancer was also viewed as a disease of modernity, a white man's disease caused by the hardships of post-colonial existence (Shahid & Thompson, 2009). A 1996 study with Anishinaabe First Nation peoples described cancer as feeling the 'presence of a stranger' inside one's body that was eating away at their insides (Hart-Wasikeeseekaw, 1996).There is no word for cancer in most Indigenous languages in Canada, suggesting that the discourses surrounding cancer can only explained and described using biomedical Western language and concepts, further annexing Indigenous cancer patients from their own culture and ways of healing (Csordas, 1989). In an article exploring the Navajo people's perception of cancer, Navajo words that roughly translate to a 'sore that does not heal', and 'keeps on rotting' were seen in their native language (Csordas, 1989). Some Indigenous cultures believe that cancer is a disease introduced during colonization, much like tuberculosis (Christie et al., 2021; Kolandooz, 2014). Furthermore, cancer is heavily stigmatized in

Indigenous communities, which may result in a delay in diagnosis and treatment (Enuaraaq et al., 2021). Attitudes toward cancer screening, treatment, and surveillance differ drastically from most Western conceptions of health and illness. For example, in a study of First Nations women's beliefs of the effectives of mammography as an early screening tool, many women believed mammography was the cause of breast cancer, demonstrating an inherent mistrust in the healthcare system (Kandasami et al., 2022). Moreover, our Western individualistic approach to disease prevention fails to encompass the more collective view of Indigenous peoples. In a study by Christie et al. (2021) examining attitudes toward breast cancer screening, researchers found that a key driver to the participation of breast cancer screening was the perception in investing and being there for the next generation, reinforcing a collectivist approach to preventative interventions.

Cultural Safety in Cancer Care

Culturally safe cancer care is very often linked in the literature to improved cancer screening, enhanced disease management, and better psychosocial outcomes for those who encounter it (Enuaraq et al., 2021; Tremblay et al., 2023). Defining exactly what cultural safety looks like however has been a difficult task, and requires an uncomfortable reckoning with our country's colonial past. It must first be acknowledged that most attempts to define thecharacteristics of cultural safety are done from Western epistemological perspectives, diluting the key element of cultural safety as being defined by those who received it (Enuaraq et al., 2021) However, a renewed interest in decolonizing healthcare has reignited the concept of cultural safety as a potential solution to the ever-widening health disparities (Allan & Smylie, 2015). To further explore the concept of cultural safety in nursing, I have divided the literature into four distinct categories: Training and education, navigation and role integration, communication barriers, and access.

1) Training and Education

Training for non-Indigenous healthcare providers is repeatedly mentioned as being an important aspect in the creation of culturally safe spaces within healthcare (Schill & Caxaj, 2019; Webb et al., 2023). Despite the call for a radical reframing of the political systems that shape health outcomes, an overwhelming amount of effort to enhance cultural safety in the workplace adopts a ‘bottom-up’ approach as opposed to a ‘top-down’ strategy, by training frontline staff to work in culturally safe ways. Rand et al. (2019) studied the impact of the CCO’s 2015 course on Indigenous Relationships and Cultural Safety (IRCS) and determined that 72% of respondents stated the course increased their knowledge on Indigenous health and First Nations Inuit and Métis (FNIM) people, but failed to explore if it resulted in an increase in culturally safe practice. In an article exploring Indigenous culturally safe training (ICST), and best practices for achieving cultural safety in healthcare, Webb et al. (2023) highlight the difficulty in keeping staff engaged with and accountable for their education, as well as issues concerning online delivery, and lack of representation of diversity within Indigenous cultures. The onus to achieve culturally safe practice is therefore placed on individual staff members and medical personnel that staff these institutions and fails to engage the larger systemic power dynamics that fuel these disparities.

2) Navigation and Role Integration

In additional to cultural safety training at the staff level, there have been several studies demonstrating that the addition and integration of new professional roles within healthcare systems that support Indigenous people's navigation of the cancer system may be an effective solution to enhancing culturally safe care (Shepperd et al., 2020; Thackrah et al., 2023; Tremblay et al., 2023). Well-designed, community-informed models of patient navigator roles in the cancer care sector have demonstrated to successfully build bridges between culturally marginalized populations and the patient care providers within these systems (Thackrah et al., 2023). These roles share similar characteristics including a person that is familiar with the culture, language, and traditional practices of a certain community. Integration of Indigenous health professionals (often elders) who can provide cultural support not only to patients but to non-Indigenous staff have demonstrated success in creating culturally safe environments. For example, a review of Cancer Care Ontario's network of ten Indigenous Patient Navigators demonstrated increased emotional and practical support for Indigenous patients as well as increased advocacy, education, and co-ordination of care (Shepperd et al., 2020). These roles however cannot simply be 'add-ons' and require deep organizational commitment to the full integration of these individuals, their roles, and the knowledge systems they work within (Thackrah et al., 2023; Tremblay et al. 2023). Achieving systemic transformation underpinned by cultural safety requires transformation at all levels of organizational activity and leadership, not simply the provider-patient level.

3) Communication

It is clear from the literature that although it is difficult to define, qualify, and recognize exactly what cultural safe care is, it is easy to recognize culturally unsafe care in the clinical setting. In this sense, culturally safe cancer care is often defined in terms of what it is *not*. A deluge of literature exploring Indigenous patients' interactions within the cancer care system have identified many barriers to the delivery of culturally safe care, resulting in damaging interactions underpinned by culturally unsafe care. Many patients discuss the lack of clear communication with healthcare providers who often use confusing medical jargon in tightly timed-constrained appointments when outlining treatment options (Sanjita et al., 2023; Thackrah et al., 2023). Body language, silences, and gestures in communication styles can also impact how messages are being delivered cross-culturally (Thackrah et al., 2023). Feelings of cultural alienation in the hospital setting can be distressing for Indigenous patients, and dismissive attitudes of traditional knowledge and holistic treatment options infused with racism are pervasive in the experience of Indigenous patients admitted to tertiary facilities for treatment (Sanjida et al., 2022). One study outlined one's experience as an elder Indigenous woman and her discomfort in being cared for by a male care provider (Thackrah et al., 2023). The presence of male-only radiographers during breast screenings was also viewed as inappropriate and culturally unsafe, offering one explanation for the disparities seen in breast cancer screenings. From the patient's perspective, a lack of cultural safety in oncology care was defined by a fundamental lack of trust within the tertiary healthcare system, and perceived dismissive and racist encounters with healthcare providers that led to feelings of alienation (Sanjida et al., 2022). Incorporating elements of Indigenous culture including artwork, language, and healing rituals into cancer care can increase trust and communication between Indigenous patients and their healthcare providers (Summers, 2023). Supporting decision-making that upholds cultural values and beliefs of indigenous patients was seen as an important aspect of culturally safe care.

4) Access

Access to primary care is often the gatekeeper for accessing oncology care and other tertiary services (Horill et al., 2022a). However, primary care and cancer screening services are often lacking in areas inhabited by Indigenous people, resulting in the need to travel long distances, and encounter financial and structural barriers of transportation (Galloway et al., 2020; Horill et al., 2018, 2022a). Furthermore, logistical and financial constraints of leaving one's community and traveling to an urban setting for treatment have a profound impact on the stress levels of Indigenous patients and impact willingness to participate in treatment (Horill et al., 2019). Patient's yearning for cultural connectedness was often dismissed by care providers and misconstrued as disengagement or incompliance with treatment (Thackrah et al., 2023). However, simply improving physical access to cancer services without addressing the systemic factors that result in these services being chronically underutilized by Indigenous people fails to address the issue at hand (Horill et al., 2022a). In an article exploring nurses' perception of access to oncology care among Indigenous people, access is often understood from a geographical perspective, and barriers are understood in a physical sense such as lack of screening sites on reserves or lack of public transport access (Horill et al., 2022b). Healthcare delivery systems must be understood as socio-relational spaces where access to care is constructed through interactions between patients and staff (Horill et al., 2022b).

Barriers to accessing oncology care for Indigenous people are often mediated by the structural racism they encounter within those spaces (Allen & Smylie, 2015; Browne et al., 2017; Reading, 2015), often resulting in delayed diagnoses, untreated pain, and other unmet health needs (Bodnarchuk et al., 2014; Kitching et al., 2020). Studies demonstrate that the design and structure of health services is equally as important as the ability to access them, and exploring Indigenous patient's beliefs about oncology care is helpful (Horill et al, 2022a; Sanjida et al., 2022). For example, in a study of First Nations women's beliefs of the effectives of mammography as an early screening tool, many women believed mammography was the cause of breast cancer, demonstrating an inherent mistrust in the healthcare system (Kandasami et al., 2022). Finally, access to culture within the healthcare system can be viewed as a mark of cultural safety. Having access to greenspace, traditional foods, and traditional healing practices is demonstrated across the literature as a key feature of cultural safety (Enuaraq et al., 2021; Gifford et al., 2020; Sanjida et al., 2022; Thomas et al., 2023).

Nurses are often the first point of contact with the healthcare system and play a key role in shaping equitable access to oncology care. Despite this, nurses often feel powerless to meet Indigenous patients' needs due to the overwhelming forces of the Western biomedical system that underpins Canadian healthcare (Horill et al., 2021; Rand et al., 2019). In a study examining nurses' perceptions of Indigenous oncology care, a lack of understanding of Indigenous culture and ways of knowing, combined with the constraints of working within a system that prioritizes time and cost-efficiency over holistic care were listed as major barriers to the delivery of culturally safe care (Horill et al., 2021).

Summary

Despite a galvanized interest in the implementation of culturally safe approaches in the cancer care sector (Gifford et al., 2019; Health Council of Canada, 2012; Schill & Caxaj, 2019; Thomas et al., 2023), confusion and ambiguity concerning how this concept is defined, and how it is enacted in the cancer care sector continues to persist. Research consistently demonstrates that Indigenous people experience poorer health outcomes and higher mortality due to cancer than non-Indigenous Canadians (Beckett et al., 2021; Cancer Care Ontario, 2015; Christie et al., 2022; Cole et al., 2021; Dasgupta et al., 2019; Gifford et al, 2019). Beginning to analyze the underlying causes of this glaring disparity is difficult as the problems faced by these communities are deeply complex, and are infused with decades of colonial violence, institutional racism, and insidious lasting effects of the damaging public policies including the Indian Act that continue to have deleterious effects on the health and wellbeing of Indigenous people and communities (Allan & Smylie, 2015; Kitching et al., 2016; Tang & Browne, 2008). Currently, no study exists that critiques culturally safe cancer care through a lens of critical disability theory, with a focus on health systems that deliver care.

Chapter 3: Theoretical Framework

This chapter outlines the theoretical approach that underpins my thesis and is informed by interdisciplinary scholars that engage with race, colonialism, and disability studies. First, I introduce critical disability theory including its origins, and antecedents. I then describe debility, the central theoretical concept of this thesis, and explore its intersections with biopolitics and neoliberalism as outlines by Puar (2017). Next, I introduce the concepts of capacity as it relates to debility and colonialism (Puar, 2017), and conclude with a discussion of Mitchel and Snyder's concepts of inclusionism and ablenationalism as a critique of liberal rights-based disability activism (Mitchell & Snyder, 2015).

Critical Disability Theory

Critical disability theory refers to a wide range of intersecting critical theoretical approaches including critical race theory, feminist/queer theory, and post-colonial theory. It emerged in the late twentieth century in response to a growing disability human rights movement and the limitation of the medical model to adequately explain the lived experience of disabled people (Meekosha & Shuttleworth, 2009; Sleeter, 2010). Critical disability theory is grounded in the broader field of critical theory that identifies and analyzes hidden power dynamics embedded in socio-political discourse. According to Burghardt (2011), critical theory seeks to expose ways of living that are often presumed to be fixed, unnatural, unmodifiable, and "challenges cultural, discursive institutions which undergird viable practices of misrepresentation, and thus offer a map toward greater understanding and informed challenge" (p. 13).

Critical disability theory is concerned with critiquing models of disability that are rooted in pathology, and frame disability as abnormal and in need of medicalized intervention (Jaffee, 2016). Critical disability theorist argue that ableism, sexism, and racism operate jointly to produce conditions of oppression for those not privy to neoliberal normative ideals (Puar, 2017). These intersecting theories borrow from each other and help to explore and unpack complex and insidious social phenomena that produce and sustain disability.

On the surface, it may not be immediately evident how critical disability theory extends itself to the study of decolonization and reconciliation in healthcare. The strength that this theory offers is its ability to challenge normative discourses of neoliberal visibility and invisibility, and to examine current power dynamics that result in the debilitation of certain populations to maintain the status quo (Mery Karlsson & Rydström, 2023). Critical race scholar Nirmala Erevelles (2014) highlights the "potential tensions that can arise when disability studies scholarship is confronted by relational analyses where the emancipation of some bodies is related to the disposability of other bodies within historical contexts that nurture such disjunctions" (para. 7). The main constituents of critical disability theory, namely sexual minorities and those with disabilities, share a common history of being pathologized by medicine and demonized by religion (Sandahl, 2003). Those who claim Indigenous identity also share a history of institutional violence and ongoing oppressive power regimes. Critical disability theory extends to the theoretical intersects of race, gender, sexuality, religion, and ability to explore nonnormative embodiments as they exist in complex relations with history, politics, and power, and contributes to a deeper, more critical understanding of the neoliberal transformations within healthcare. Ablism and racism operate jointly, intensifying and borrowing from each other, and call for an intersectional analysis of the power dynamics that create and sustain hegemonic societal organization.

Debility – Beyond Foucault's Biopolitics

The concept of debility was first developed by Jaspir Puar in her ground-breaking work *The Right To Maim* (2017) and describes a modern neoliberal and neocolonial eugenic that has emerged in late capitalism. Intersecting with population control and racialized violence, Puar builds on Foucault's concept of biopolitics by applying it through the lens of ongoing sanctioned settler colonial violence and racialized terror.

Biopolitics

Biopolitics emerged as a school of thought alongside the creation of epidemiology, public health, and the health of populations as a collective. The Foucauldian definition of biopolitics concerns itself with the politics of managing, governing, and controlling people as individuals and as a collective, specifically with the creation of 'problem populations' (Warbrick et al., 2016). Through novel techniques of tracking, counting, graphing, and comparing statistics such as birth rates, death rates, fertility rates, economy and poverty statistics and rates of disease, certain populations (and individuals within those populations) were labelled as problematic, and in need of government intervention, monitoring, and control (Foucault et al., 2008). Foucault theorized biopolitics as a mechanism by which the governing economic and political systems can be maintained through the targeted regulation and control of deviant or abnormal populations, reinforcing a normative understanding of societal worth (Foucault et al., 2008; Fraser, 2023).

Biopolitics can be viewed as the process by which certain bodies are deemed less valuable, less worthy of health, and more prone to injury, illness, and disability. Foucault posits that biopolitics is a technology of power that take the aggregate of the biological, such as the health of population, as an object for political intervention. As Foucault put it, the logics of biopolitics is to make live and let die (Foucault, 2008). Puar's definition of biopolitics builds on

Foucault’s conception and captures an insidious form of racism embedded in everyday life, where the goal of the state is to produce populations that do not die, but are kept in a state of constant maiming, exploitation, and infrastructural neglect (Puar, 2017). Puar views biopolitics as the modern practice of rendering certain populations available for statistically likely injury in comparison to other populations. For Puar, biopolitics is the mediating agent that creates the conditions to make someone live, without letting them die (Puar, 2017), and intersects with Berlant’s (2007) idea of ‘slow death’ or the “condition of being worn out by the activity of reproducing life” (p. 759). Slow death is a distinction “between individual life and collective living on, where living increasingly becomes a scene of the administration, discipline, and recalibration of what constitutes health” (Berlant, 2007, p. 756). The distinction between ‘letting die’ and ‘making live’ is an important one, as Puar views slow death and debility as a purposeful and engineered alternative to ‘letting die’, that is, economically and financially profitable and necessary to sustain the status quo of ordinary life under a neoliberal reign.

Neoliberalism

Neoliberalism is a dominant force shaping health discourses in Canadian society, emphasizing individual behaviours and moral responsibility as drivers in health-related decision-making (Hokowitu et al., 2022; Prussing & Newbury, 2016). More insidiously, neoliberalism emphasises participation in capital markets above all else, continuously producing individuals who depend on the market economy not only to thrive but to survive (Puar, 2017; Shildrick, 2015). In recent years, scholars increasingly recognize the link between political ideologies and health outcomes, attributing poor health outcomes to Western colonial and neoliberal models of government (Poirier et al., 2022).

Championed by politicians Ronald Reagan and Margaret Thatcher in the late 20th century, neoliberalism is both a political rationality and policy model that emphasizes the value of free market competition. Core principles of neoliberalism include personal autonomy, competitive private markets, reduced public expenditure on health and social services, and economic deregulation to support free markets (Poirier et al., 2022; Prussing & Newbury, 2016). As a political ideology, neoliberalism is tightly associated with individual autonomy, free markets, endless economic growth with minimal state intervention except to protect the economy, and wealth accumulation. However, neoliberal policies operate using highly coercive and tacit power dynamics and have had deleterious effects on human lives, most pronouncedly in marginalized communities and those of lower socioeconomic status (Poirier et al., 2022).

The emphasis on individual autonomy in neoliberal discourse sharply contrasts with a collectivist and community-based orientation held by many Indigenous communities. In addition, neoliberal values assert that individuals have the capacity to make rational health decisions, emphasizing a behavioural model of health that blames the individual for their health problems. In this context, neoliberal rationality emphasizes an objective scientific understanding of human relationships and considers the human being as homo economicus, where decisions are guided by an economic framework (Al-Chami, 2024). Under neoliberal rule, a strong association between morality, rationality, and health status exists assuming that the only ethically reasonable response to poor health is for individuals to engage in the biomedical system as ‘rational consumers’ of commodified healthcare.

Debility

In *The Right to Maim* (2017), Puar refines the concept of debility through an analysis of the complex political relationship between Israel and Palestine and the violent attacks on

Palestinian bodies that render them disabled. Puar (2017) explores the act of sanctioned maiming that results in endemic impairments and disablement of Palestinian people, and positions maiming as a sanctioned tactic of settler colonial rule that extracts value from racialized/marginalized people without debilitating the broader public:

> The right to maim exemplifies the most intensive practice of the biopolitics of debilitation, where maiming is a sanctioned tactic of settler colonial rule, justified in protectionist terms and soliciting disability rights solutions that, while absolutely crucial to aiding some individuals, unfortunately lead to further perpetuation of debilitation. (p. xix)

Deliberate maiming is “a status unto itself, a status that triangulates the hierarchies of living and dying that are standardly deployed in theorizations of biopolitics" (Puar, 2017, p. 137). Sanctioned maiming to purposefully debilitate is ill-conceived in current biopolitical discourses and eludes human rights frameworks that dominate the Global North. It is a practice that escapes legal, and political definitions thereby making it difficult to identify and mobilize against (Fraser, 2023). Debility describes the innumerable amount of people that are not only debilitated or weakened by illness, exhaustion, or disability, but those whose lives simply exist and persist without ever getting better (Berlant 2007; Puar, 2017).

Debility and Capacity as Mediators of Disability

Puar (2017) breaks down the binary of abled/disabled by arguing that although certain people do not fit the criteria for being disabled, they are not granted all the privileges that accompany being able-bodied (Puar, 2017). Instead, she argues that disability exists on a continuum mediated by the concepts of debility and capacity, whereby certain individuals are capacitated through disability-rights discourses that temporarily grant them access into the world of ableist norms:

> I argue, first, for a critical deployment of the concepts of debility and capacity to rethink disability through, against, and across the disabled/non-disabled binary … situate disability in relation to concepts such as neoliberal and affective capacitation, debilitation, and slow death; 'slow death' is in some sense a mode of neoliberal and affective capacitation or debilitation as mediated by different technological assemblages. (Puar, 2017, p.2)

Capacitation refers to the way in which governing structures and institutions invest in certain bodies, often to advance political agendas or for labor and military use, while simultaneously debilitating others. Who gets selected for capacitation is often a reflection of racial, political, and economic hierarchies:

> The withering of some disabled lives and the capacitation of others result from neoliberal material and discursive processes that orient and imagine disability as a life without a future unless capacitated through such biocapitalist practices as cures or body/mind enhancement technologies and procedures. (Fritsch, 2016, pp. 11–12)

Puar critiques the disability rights movement, the dominant framework for disability activism in the Global North, as adopting a capacitation approach that is often in line with neoliberal conceptions of transient ableism and settler-colonial logic. Disability, she argues, is viewed as the loss of able-bodied whiteness, and fails to capture the thousands of people that are systematically disabled through war, terror, and colonial occupation: "The biopolitical distribution between disability as an exceptional accident or misfortune, and the proliferation of debilitation as war, as imperialism, as durational death, is largely maintained through disability rights frameworks" (Puar, 2017, p. 66). She employs the example of ongoing violence in the Global South to demonstrate how Palestinians are systematically debilitated through bodily maiming, malnutrition, and restricted movement – a violence that is not recognized within formal disability-rights discourses framed in the Global North. It should be noted that this analysis preceded the October 7, 2024 attacks in Israel, and the ongoing violence resulting in tens of thousands of deaths of Palestinian people.

In settler-colonial contexts, debility is a viewed as a strategic technique enacted by government forces to weaken certain populations to ensure continued fiscal extraction, labour, and compliance (Puar, 2017). What is of particular importance here is not only the production of debility to sustain hegemonic power dynamics, but the inherent profitability of debility itself (Shildrick, 2015). Debilitated bodies enter deep consumer relationships with for-profit companies (e.g., pharmaceutical industry, rehabilitation industry), with the taunting promise of a better life and a better future, simultaneously ensuring that this will not ever happen (Puar, 2017; Shildrick, 2015). The concept of debility explores a more modern and insidious form of racism embedded in everyday biopolitics; a shift from the overt warfare as described by Foucault to a more tacit form of eugenics driven by neoliberal forces enacted on the body itself (Puar, 2017). Critical theorist Nirmana Ervelles expands on the concept of debility as it related to disability, stating, "… there is no respite from the harsh living conditions of poverty nor from the exploitative social relations of production and consumption or from the historical continuities of (neo)colonial wars and a (neo)imperialist political economy—all of which produce, propagate, and proliferate disability while simultaneously rendering disabled people completely invisible" (Erevelles, 2014, para. 6). Debility is not simply a by-product of neoliberal late capitalism, but an essential and sustaining element of it. Without the purposeful and systematic debilitating of certain bodies and populations that include Indigenous people in Canada, the neoliberal hierarchy is unable to be sustained “Biopolitics deployed through its neoliberal guise is a capacitation machine; biopolitics seeks capacitation for some as a liberal rationale (in some cases) or foil for the debilitation of many others. It is, in sum, an ableist mechanism that debilitates” (Puar, 2017, p.xviii). Debility is an ongoing process sustained by large capitalist and (neo)colonial machines and is embedded in everyday life.

Inclusionism

Developed by disability theorists David Mitchell and Sharon Snyder, inclusionism refers to the idea whereby certain individuals from marginalized groups are granted access into neoliberal forms of inclusion (and all the benefits that accompany such citizenship) insofar as it “does not demand an excessive degree of change from relatively inflexible institutions, environments, and forms of belonging” (Mitchell & Snyder, 2015, p.14). Inclusionism, according the Mitchell & Snyder (2015), refers to a process by which people with disabilities are selectively incorporated into society in ways that align with neoliberal values such as economic productivity, individual responsibility, and self-sufficiency. Political forces obscure the destitution of disabled lives by acting as if national inclusion projects are a successful mark of Western countries. Neoliberal inclusionism projects normative values of able-bodiedness, heteronormativity, and Western ‘rationality’ onto subjects of inclusion, giving these subjects transient and temporary access to the benefits of normative neoliberal citizenship (Mitchell & Snyder, 2019a). This new form of inclusionism seeks to reify and solidify mainstream discourses of ablebodiedness and Westerns epistemologies instead of giving rise to new forms of embodied knowledge and consciousness. To further expand on their concept of inclusionism, Mitchell and

Snyder (2015) discuss the ‘able-disabled’ body, meaning bodies that are seen as emerging from the margins of disability through self-improvement means, to gain entrance into the discourse of late-capitalism, leaving most other disabled people behind. In their scathing review of inclusionist practices, Mitchell and Snyder state, “Inclusionism’s primary purpose of molding crip/queer bodies into tolerated neoliberal normativities scores a less than passing mark” (p.79).

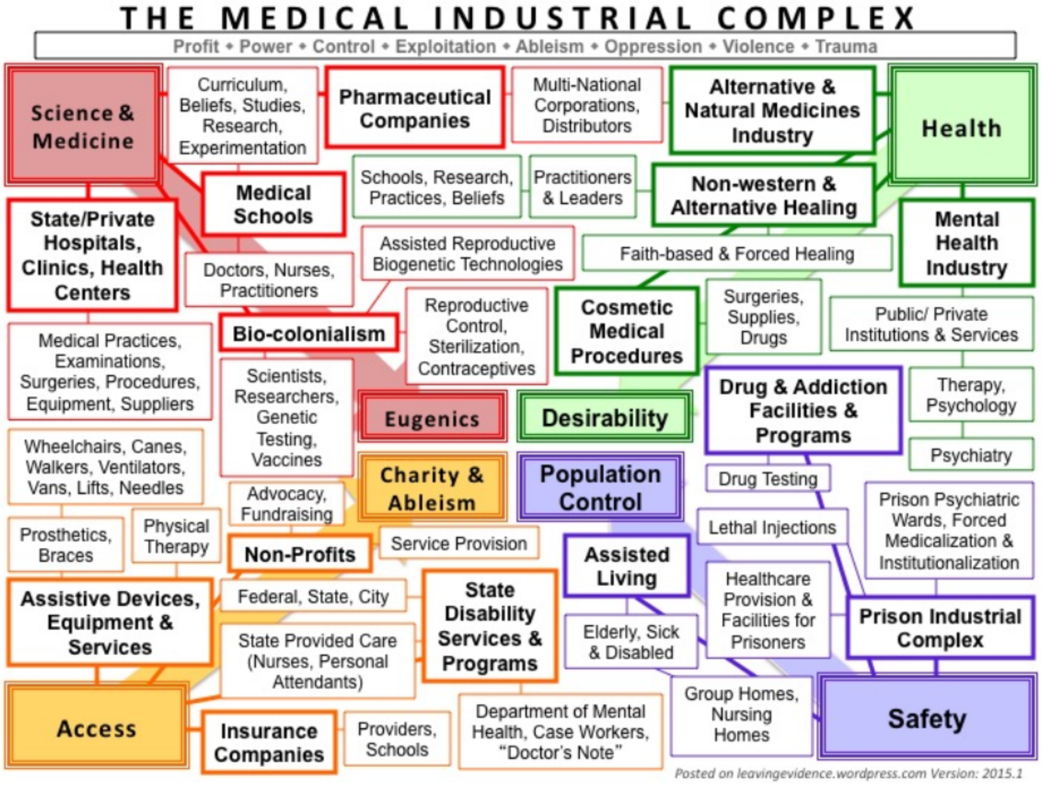
Ablenationalism

Another grounding concept of critical disability theory, ablenationalism, helps to explore the portrayal of disabled people in neoliberal forms of discourse. First developed by disability theorist Mitchell and Snyder (2015), ablenationalism builds on the concept of ableism in disability studies and refers to the “implicit assumptions that a minimum level of corporeal, intellectual, and sensory capacity, in conjunction with subjective aspects of aesthetic appears are required of citizens seeking access to the full benefits of citizenship” (p.124). These individuals are involved in a production process whereby their bodies are made disposable in an effort to highlight narratives of neoliberal inclusion, acceptance, and progress (Mitchell & Snyder, 2015; Puar, 2017). What McRuer (2006) describes as a “discursive climate of tolerance” (p.18), certain bodies are essentially repurposed, plucked from socioeconomic despair to further solidify capitalist discourses of modernity. They are in this sense not oppressed but produced and reinvigorated for the purpose of modernizing the neoliberal agenda to fit one of inclusion and acceptance and, in the case of Canada’s relationship with Indigenous people, reconciliation.

To further illustrate the concept of ablenationalism, Puar (2017) conceives the Paralympics as an ablenationalist project when considering critical disability theory. In neoliberal discourse, one’s health and citizenship in society is one’s individual responsibility centered around freedom and rational choice. This responsibilization narrative of disability places the failures or successes of ‘overcoming’ disability on the individual, rather than on the nation state. Those with disabilities are granted tentative and temporary citizenship within forums of hyper-patriotism (such as the Olympics) and hyperprosthesis (an enhancement of the disabled body through biomedical reinforcement and capacitation) that highlight narratives of inclusion and progress without having to fundamentally change systems to incorporate all people with disabilities (Puar, 2017). Within an ablenationalism’s framework, para-athletes with muscular bodies and bio medicalized mechanical limbs represent the new potential for the disabled and to not reach this point is one’s own fault, a sign of weakness or laziness that disavows the neoliberal government of any responsibility.

Figure 1

The Medical Industrial Complex



Posted on leavingevidence.wordpress.com Version: 2015.1

Note: Figure 1 depicts the Medical Industrial Complex, an intricate networks of for-profit companies including pharmaceutical organizations, medical device manufacturers, and healthcare personnel. Puar highlights the intersection between profit, power, colonialism, ableism, and oppression, and the myriad ways these forces shape health outcomes for people existing outside the limits of neoliberal ableist norms. From, *the Right to Maim: Debility, Capacity, Disability*, by J. K. Puar, 2017, Duke University Press. Copyright 2017 by Duke University.

Conclusion

Critical disability theory offers a unique analytic lens to address the issue of cancer care in Indigenous communities by reconceptualizing and reframing our understanding of health, ablism, and the biopolitical control and debilitation of marginalized bodies. By allowing for a larger systems approach that considers the powerful machines of capitalism and neoliberal rights-based discourses that shape today's health outcomes, critical disability theory explores how certain bodies are pathologized over others and made to pay for the upholding of the status quo. The concepts of debility, capacity, inclusionism, and ablenationalism provide a framework for understanding how certain lives are inherently valued over others, and how health systems act as debilitating machines that uphold settler colonial regimes of power. As reconciliation efforts with Indigenous peoples in Canada are ongoing, a critical perspective of culturally safe care must be considered to help re-oriented our healthcare system to better serve Indigenous communities dealing with cancer.

Chapter 4: Methodology and Methods

This chapter describes the methodological approach and methods that underpins this thesis, and their fit within the context of my research questions. This study is a secondary analysis of narrative data collected from a previous study (hereafter referred to as the “primary study”) that explored transitions in cancer care with the Algonquins of Pikwakanagan First Nations community in November of 2023. I begin this chapter with an overview of the primary study including the setting and methods that were used to collect the data that informed this thesis. Subsequently, I discuss reflexive thematic analysis (RTA), the chosen methodology used for this thesis, and it's fit within the context of Indigenous research and knowledge creation. Next, I describe the process of thematic analysis in accordance with the principles of RTA including ongoing reflexivity and acknowledging my positionality to the research topic as a registered nurse, researcher, and cancer survivor. Lastly, I discuss the research steps taken to uphold privacy and confidentiality, and the ethical dimensions of this study.

Overview of the Primary Study

The title of the primary study from which the data for this thesis was derived is *Adapting Transitions-in-Care (TiC) Strategies for Cancer Care to be Culturally Relevant with First Nations Communities*. Transitions in care (TiC) are defined as the actions taken to coordinate care as patients are transferred across health settings. These transitions can be challenging to navigate and can lead to exposures to gaps of care that can result in negative health outcomes for patients (CIHR, 2021). The study was funded by the Canadian Institute of Health Research (CIHR) and the nominated Principal Investigator Dr. Wendy Gifford, with the aim of exploring culturally safe TiC strategies with the Algonquins of Pikwakanagan First Nations survivors of cancer, their family members, and local healthcare providers to navigate the cancer care system.

First Nations people possess unique TiC challenges as they navigate the cancer care system along the cancer care continuum, from prevention into survivorship. The objectives of the primary study were to:

1. Collaboratively determine a TiC strategy for system navigation with First Nations people who have experienced cancer.
2. Co-design an evaluation framework for evaluating the TiC strategy, including data collection methods that are meaningful to the community.
3. Develop a TiC strategy and evaluate outcomes including: acceptability and utilization and influence on system navigation.

The TiC strategy that community members identified was in the form of a resource binder of information to assist them to navigate the health care system more seamlessly and effectively. The binder also provided information and resources about cultural knowledge and practices that community members identified as helpful when experiencing cancer and navigating the cancer care journey, from diagnosis, symptom management, palliation and survivorship.

The Algonquins of Pikwakanagan First Nation

The Algonquins of Pikwakanagan are a First Nation community located on the shores of Golden Lake in Renfrew County, and along the Ottawa River. The word Pikwakaganan roughly translates to ‘the place where the water flows’ symbolizing a deep connection to the land as a source of sustenance, transportation, and cultural significance. With over 2000 members and 500 individuals living on the reserve (Gifford et al., 2023), the Algonquins of Pikwakanagan share a rich cultural heritage that includes living off the land, engaging youth in cultural traditions. and revitalizing cultural practices amidst ongoing challenges of colonization.

Data collection for the primary study included one sharing circle with cancer survivors and their families (n=6 people), one focus group with health and social care providers from the community including nurses and personal support workers (n=6 people), and six individual interviews with cancer survivors and family members. Semi-structured interview questions were used to guide the sharing circle, focus group and interview discussions. The data was collected in November and December of 2023 after the Pikwakanagan study team developed and distributed a TiC tool to individuals diagnosed with cancer or family members supporting or having supported someone with cancer. The tool took the shape of an information binder titled, *My Healing Journey* and included information on cancer symptoms, staging, treatment options, as well as information on transport, housing, and community resources.

The study was co-lead by Dr. Wendy Gifford, professor in the School of Nursing at the University of Ottawa and Peggy Dick, citizen of the Pikwakaganan First Nation, Registered Nurse and Supervisor at Pikwakanagan Home Care Services. Gifford and Dick have a longstanding respectful research relationship for over 15 years working with the community. I served as a research assistant on the primary study and was part of the analysis team that created the final presentation that was brought back to the community for member checking and validation in 2023.

Reflexive Positionality

When I first set out to select a thesis topic, I hoped to study cancer survivorship in First Nations communities in Ontario. I hoped to explore their access to follow-up care, surveillance, psychosocial support, and late-effects monitoring – all things that I have struggled so deeply with throughout my twenty-year remission. What struck me so profoundly in the sharing circles with cancer survivors and family members of people who had cancer was how few people made it into survivorship. How many were suffering from the sudden and needless loss of a loved one to late-stage cancer. This community was struggling not with the messiness of survivorship and re-integrating into life post-cancer treatment, but with a deep grief of losing their loved ones too soon. A frustration of repeatedly losing the battle against a healthcare system that systemically ignored their health needs and placated their traditions, and a political system that has created sub-optimal conditions for daily living including restricted access to safe drinking water and healthy foods. I began to realize that there must be a different way of delivering care that embraced and enveloped a new kind of knowing and healing that felt so foreign to the way I had been educated as a nurse. But as is so often in research, I am not the first to explore this question. The concept of cultural safety as a framework for approaching care that espouses to locate the health of Indigenous peoples within the context of ongoing colonial violence has been at the forefront of health equity endeavors for past few decades, particularity within the context of nursing. However, a thorough critical exploration into what is defined as culturally safe cancer care with First Nations communities is lacking. I set out to explore what culturally safe cancer care meant to First Nations people, particularly in the context of the deluge of reconciliation efforts put forth by Western colonial healthcare institutions, and how their definition can add to our understanding of culturally safe cancer care.

The Current Study

The current study is a secondary analysis of data collected during the primary study. A secondary analysis involves investigations where data collected for a previous study is analyzed to explore new questions or using different analytical strategies (Ruggiano & Perry, 2019). A secondary analysis of previously collected data is demonstrated to be a useful, time-efficient and cost-effective tool for the generation of new research questions and interpretations (Smith et al., 2011). Advantages of using raw data in secondary analysis, instead of relying on themes and coding previously interpreted through published studies (such as in a qualitative meta-synthesis) allows for a more abstract interpretation and can present a new way of understanding the data (Beck & Tatano, 2018). Furthermore, using previously collected data reduces participant burden, and is free from the perspective of the original researcher (Beck & Tatano, 2018). Another advantage of secondary analysis is its ease of access to hard-to-reach populations. In the case of working with First Nations people, especially those living on reserve, secondary analysis is therefore a strong fit as implementing a new study could be confounded by geographical, financial, and ethical barriers.

While secondary analysis offers valuable opportunities to advance knowledge in a time-efficient and cost-effective manor, there is much criticism surrounding secondary analysis and its many methodological and ethical problems. One problem highlighted by scholars is that the sociopolitical forces that shape the data collected might be different at the time of re-analysis in the secondary analysis (Ruggiano & Perry, 2019). This challenge can be mitigated when the data is analyzed concurrently or in a similar time frame as data from the primary study. Lastly, it is crucial to determine a good fit between the research question and the selected data set before engaging in secondary analysis, and whether the original researcher had been privy to understanding certain contexts and nuances that influenced the direction of data analysis (Beck & Tatano, 2018).

Considering the strengths and challenges of conducting a secondary analysis, the guiding research questions for the current study are:

1) How does critical disability theory help better understand the experiences of cancer in Indigenous communities?

2) How do community members of the Algonquins of Pikwakanagan First Nations view cultural safety in cancer care?

My research questions are a good fit with this data set for several reasons. I worked as a research assistant during the primary study and participated in data collected, thus data collection and analysis were concurrent with the primary study. With the current study closely aligned to the objectives of the primary study, I employed a different methodological and critical framework to analyze the data. Moreover, the use of secondary analysis to answer new research questions reduces overall community burden and research-related risk, and is especially fitting when conducting research with populations that may be marginalized or vulnerable to exploitation (Beck, 2023). Finally, Peggy Dick, a co-PI on the primary study and member of the Algonquin's of Pikwakanagan First Nation community took interest in the data from the study being used for this research topic. See Appendix G for their community letter of support for this study.

Research Design

Braun and Clark released their inaugural work on thematic analysis in 2006 and elaborated extensively on the methods and elements that constitute thematic analysis in 2019 to develop a clearer conceptualization, referred to as *reflexive* thematic analysis (RTA) (Braun & Clark 2019; Bryne, 2022). Through its flexibility as a method and theoretical freedom rather than a fully embedded methodology, RTA can be undertaken with a range of guiding theoretical and epistemological approaches, however it is purely qualitative (Braun & Clark 2006; 2020) and "eschews any positivistic notions of data interpretation" (Byrne 2022, p. 1393). Braun and Clark (2006) describe RTA as compatible with constructivist research methods "which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society" (p. 81).

Building upon the steps of content analysis, RTA emphasizes the researcher's active role in knowledge production through an ongoing reflection and nuanced understanding of the researcher's positionality to the data (Braun & Clarke, 2019; Byrne, 2022). The central tenet of RTA is the notion of reflexivity, defined as an act of bending back upon oneself where the mind observes and examines its own experiences and emotions, intelligent self-awareness, and introspection (Byrne, 2022). This practice is embedded in every step of the research process, and situates the researcher not only as contextually rooted in their own unique set of lived experiences, values, beliefs, and assumptions, but as an active producer and creator of knowledge. RTA champions an iterative, creative approach free from pre-conceived theories or analytic tools (Braun & Clarke, 2020) and facilitates identification and analysis of patterns or themes in a given data set through the researchers "reflective and thoughtful engagement with their data and reflective and thoughtful engagement with the analytic process" (Braun & Clarke, 2019, p. 594). RTA uses an inductive approach to data analysis, meaning that themes are not pre-defined, but are systematically constructed through iterative, and bidirectional engagement with the material.

RTA was selected to analyze this data set as it emphasizes that knowledge is constructed through the experience of the researchers and participants and does not simply emerge passively from the data. RTA views the centrality of the researcher as its main strength. Braun and Clark viewed RTA as "creative, reflexive and subjective, with researcher subjectivity understood as a resource, rather than a potential threat to knowledge production" (Braun and Clarke, 2019, p. 7).

Epistemological considerations in RTA

For this study, the analysis was rooted in a constructivist epistemological standpoint, acknowledging the bidirectional relationship of language and meaning, viewing language as implicit in the social production of meaning and experience (Byrne, 2022; Schwandt, 1998). A constructivist epistemology is my philosophical stance that emphasizes the subjective construction of knowledge. Through a constructivist epistemology, I recognize that my own backgrounds, perspectives, and assumptions shaped the research process and my findings. I acknowledge that knowledge is context-dependent, and reality is socially constructed through human experiences and interpretations (Braun & Clarke, 2006). Themes that were constructed from the data reflect participants' perspectives and my own interpretations of their words.

According to Braun and Clarke (2019), deductive approaches to coding are associated with an essentialist/positivist approach and often provide less rich description of the overall dataset. Inductive, data-driven coding was used to guide the thematic analysis of the data. 'Open-coding' free from theoretical constraints and using words of participants was used to best represent meaning conveyed by the participants (Byrne, 2022). However, it is important to note that coding analysis rarely falls into one distinct category of either inductive or deductive coding and instead tends to fall somewhere on the continuum (Braun and Clarke, 2013; 2019; 2020). Although principles of inductive coding guided the analysis, the overall theoretical framework, as well as the researcher positionality played an active role in shaping interpretations of the data. Effort was made to stay as close as possible to the participants original words. A theory-driven analysis took place, and the themes are described in the following chapter.

Finally, Braun and Clarke discuss the use of experiential vs. critical approaches to data interpretation and analysis. An experiential orientation seeks to explore how a given phenomenon is experienced by a participant (Byrne, 2022). The phemonenon itself, in addition to the meaning the participant ascribes to the phenomenon, are important elements in an experiential approach (Braun and Clarke, 2014). Conversely, a critical orientation to data analysis seeks to "examine the mechanisms that inform the construction of systems of meaning, and therefore offer interpretations of meaning further to those explicitly communicated by participants" (Byrne, 2022, p. 1396). A critical orientation approaches discourse as if it were constitutive, rather than simply reflective of a participant's experience (Braun & Clarke, 2014). In this case, a critical orientation was more fitting to this study, as it required a broader understanding and consideration of the social institutions in which these experiences took place.

RTA with Indigenous Communities

Non-Indigenous settler-colonial researchers have a long and sordid history of exploiting Indigenous communities in the name of knowledge advancement, and Indigenous communities have too often been researched on, rather than with (Hammond et al., 2018; Kovach, 2021; Smylie et al., 2009; Thomas et al., 2023). Researchers have most often used methodologies which exist far outside Indigenous values and fail to incorporate Indigenous knowledge (Drawson et al., 2017). It is of crucial importance that I, as a non-Indigenous researcher, position myself to the data, and acknowledge the assumptions and preconceptions that I bring to this project. Indigenous methodologies and approaches to knowledge creation are vastly different than Western scientific approaches, being more dynamic, and emphasizing a cyclical and fluid approach (Kovach, 2021; Poirier & Neufeld, 2023). Indigenous methodology seeks to uphold Indigenous cultural sustainability through the respectful restoration of that culture's knowledge system (Kovach, 2021). Kovach (2021) describes four central tenants of an Indigenous conceptual framework: 1) the fundamental beliefs about knowledge creation (Indigenous epistemology), 2) axiological premises (ethical and spiritual dimensions), 3) respecting the land and place (Indigenous community), and finally 4) the experiencing self in relationship. These four core elements encompass a respectful approach to indigenous knowledge creation and make Indigenous methodologies inherently different from other qualitative research frameworks.

As policy and programming grow out of research outcomes, Indigenous knowledge, traditions, and practices must hold a place in formal academic and research spheres. More importantly, a methodology that is respectful and representative of Indigenous belief systems must be used. To this end, I believe that RTA is a fitting methodological approach as it emphasizes a cyclical, reflective, and dynamic approach to knowledge creation. As a non-Indigenous researcher, I do my best to avoid misrepresentation and misinterpretation in my analysis. However, a strength of RTA is that it acknowledges that this is simply not possible as each researcher brings their individual experiences and assumptions to their analysis (Braun & Clarke, 2006). I chose this method as it enables me to reflect on my own role in perpetuating colonial practices, while amplifying the voices that have been missing from health research for too long. This methodology is in line with the TRC's Calls to Action #18 and #19, which seek to acknowledge that the current state of the health of Indigenous people is a direct result of harmful governmental policies and close the gap in health disparities between Indigenous and Non-Indigenous communities (TRC, 2015).

Ethical Considerations

Approval for this study was obtained from the University of Ottawa Research Ethics Board (uO REB #H-04-24-10332). See Appendix H for REB approval. Dr Wendy Gifford, the principle investigatory on the primary study at the University of Ottawa and Ms. Peggy Dick, primary co-applicant and citizen of the Algonquins of Pikwakanagan First Nation granted permission for the data to be used for this secondary analysis. Ethical considerations for working with Indigenous communities strongly underpinned this research project throughout every stage, from generating the research question, to data collecting, to interpreting results. The Tri-Council Policy Statement: Ethical Conduct for Researching Involving Humans (TCPS2), specifically Chapter 9: Research Involving the First Nations, Inuit, and Metis People of Canada (CIHR, 2014), as well as the First Nations Information and Governance Center (FNIGC) principles of ownership, control, access, and possession (OCAP) guide every step of the research process. Furthermore, in their foundational work "First Nations and Higher Education" Indigenous scholars Kirkness and Barnhardt (2016) describe the four Rs of research Respect, Relevance, Reciprocity, and Responsibility. These four Rs are recognized and supported in Kovach's (2021) work in Indigenous research methods, and are woven into each step of the research process to help co-create knowledge that will belong to the Algonquin's of Pikwakanagan First Nation community.

In a secondary analysis, risk of misappropriating and misrepresenting the data is always a concern. In line with the principles of OCAP, the Algonquins of Pikwakanagan own the research data, and have the option to retain all research records after the study in completed. At this time, the data is being held in trust on the university of Ottawa secured driver as requested by community partners (see data management and storage below). Staying true to the data by engaging in constant reflection and basking myself in Indigenous knowledge and methodologies occurred throughout the analysis process. Supporting documents and purpose of study were submitted to the University of Ottawa REB for approval. See Appendix A for confirmation of REB approval.

Data Management and Storage

All electronic data stored is encrypted and password-protected per the University of Ottawa Research Ethics Board Guidelines. Moreover, privacy and confidentiality are paramount when analyzing personal and sensitive data obtained through interviews and focus groups. In the primary study, all transcribed data was de-identified and stored on the University of Ottawa's encrypted and password-protected cloud-based storage system OneDrive. All physical data including recording devices, consent forms, and interview notes from the original study were kept in a locked cabinet at the university in the office of the Primary Investigator. The computer used for the secondary analysis was purchased for the primary study and is password protected. The codebook containing study data was shared using the University of Ottawa secure OneDrive platform. All files were password-protected and shared using the university's secure platform.

Methods

I followed Braun & Clarke six phases of thematic analysis (Braun & Clarke, 2006, 2019, 2020). While the phases are organized in a stepwise fashion, the iterative nature of the RTA process requires the researcher to revisit phases of coding as meaning emerges from the data (Bryne, 2022). Table 1 depicts the six phases of thematic analysis according to Braun and Clarke (2006). I next expand on how each of these phases were conducted.

Table 1

Braun and Clarke's Phases of Thematic Analysis (2006)

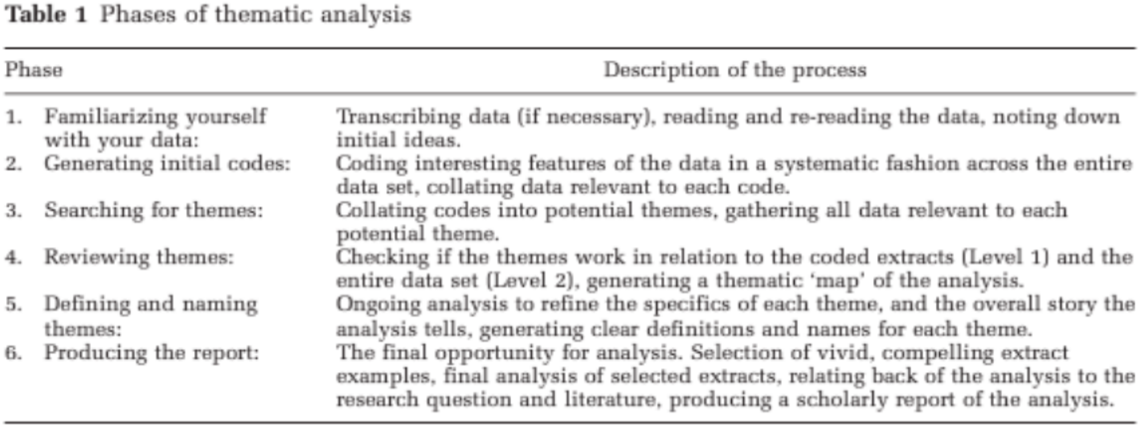


Table 1 Phases of thematic analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Phase 1: Familiarizing Oneself with the Data

As a research assistant on the primary study, I was present for the sharing circle and focus group, both conducted in the Pikwakanagan First Nations community in the Elder's Center and the Wellness center, respectively. Being present for the in-person discussion groups allowed for a closeness to the data as I was able to witness first-hand emotional accounts of cancer battles and intimate recounts of grief and loss. All audio data collected from sharing circles, focus groups, and interviews were transcribed verbatim by a professional transcriptionist and both the audio files and transcriptions were shared with me. I listened to the recordings in their entirety several times, taking notes of salient topics and potential themes. The transcriptions were reviewed in their entirety, therefore fully immersing myself in the data set and familiarizing myself with the depth and breadth of the information. During this process, I kept an informal notebook with initial ideas, memorable quotes and phrases that may be helpful in guiding the thematic interpretation later in the process.

Phase 2: Generating Initial Codes

The second phase of RTA involves the systematic generation of codes from the raw data set through the organization of data into meaningful segments that are of interest to the researcher (Braun & Clarke, 2006). A code is the most basic segment of the raw data that can be assessed in a meaningful way. All transcripts were uploaded to NVIVO 14.0 qualitative data analysis software. Using an inductive data-driven approach, in-vivo quotations by participants were coded into segmented categories with the goal of reducing as much researcher interpretation and inference as possible. Although the disability theory framework underpins this analysis, theoretical categories were not predetermined, allowing for more authenticity in coding categories. The coding process was iterative, and I revisited the data set multiple times to ensure nothing was missed. A codebook was created with supporting quotes from participants outlining my systematic inductive coding process from raw data to code to subtheme groupings.

Phase 3: Generating Themes

In this phase, the purpose of analysis "shifts from the interpretation of individual data items within the dataset, to the interpretation of aggregated meaning and meaningfulness across the dataset" (Bryne, 2022, p. 1403). The coded data is analyzed to see how the patterned codes may be categorized into larger groups to produce meaning at a higher level of interpretation. For this analysis, I first allocated all codes into subtheme categories which allowed for a clearer analysis of potential groupings of meanings. Codes were then expanded into subthemes inductively, which were then grouped into thematic categories based on similarities. All subthemes were reviewed, reworked and revised numerous times in consultation with my thesis supervisor (WG). Table 1 shows an example of theme development from an initial in-vivo code.

Table 2

Example of Developing Themes from an Initial Codes

Quote from Participants	In-Vivo Code	Generation of Inductive Subtheme	Proposed Overarching Theme
You might be able to feel fine and be able to take the medical transportation from the community here, if they're able to take you every day. ***But some people get a lot worse side effects and you can't travel****, And that happened to me, we had to rent a place to stay down there for the whole seven-and-a-half weeks. I had the diarrhea so bad that it would have been impossible for us to drive back and forth*	***But some people get a lot worse side effects and you can't travel,***	Hard to Access care	Cancer Care as A Colonial Machine of Debility and Slow Death
whether it's for insurance or for unemployment, take them and get	They take forever to start	Hard to Access Care	

them filled out right away so you can get those forms submitted because ***they take forever to start paying you anything***.	paying you anything		
some people are going to want that but then I mean, if you find out that you got really bad, then other people are just going to kind of accept it and… just like even my uncle, he just said, 'You know, ***I don't want any of this stuff****.' He was already ready"*	I don't want any of this stuff	I Don't Want Treatment	
They're not giving you choices. ***They're not giving you options*** *or anything like that and if you don't question it, and get the information, if you don't feel that it's right or if you want to know more, it's your body."*	They're not giving you options	Mistrust of System	
Those doctors, they have a protocol they follow for the treatments depending on what kind of cancer and the stage that you're at. ***It's like a cookie cutter thing****. You know, I know I was told before they even had results back from the biopsies that, 'well this is how you're going to be treated. You're going to have chemo, radiation and then you're going to have brachytherapy and then the doctor walked out of the room,' you know.* ***No questions. No nothing***	It's like a cookie cutter thing…., No questions No nothing	Mistrust of the System	
It was taken from us, the way we practiced, but today's society, with a lot of us receiving our education and a world that's evolving, we realize, the Western world realized, the traditional realized, ***we need to be together***	We need to be together	Integrating Western and Traditional Medicine	New Dimensions Care: Thinking Outside the Biomedical Box
The traditional world is always there. There's always a little portion that they're looking for to keep it alive even if it's one word. ***Speaking the ancient Algonquin, I'm not***	***the ancient Algonquin.***..it's in our DNA	Culture is Medicine	

surprised that you know it by heart because it’s on our DNA*, it’s in cells. And when we pray, it’s in our DNA, it’s in our cells. They’re ancient prayers that come out of us. They’re ancient knowledge that comes out.*			
Elders do ceremony. The ceremony could be, it could be the ***healing circle itself and seeing the power of the circle***	*the healing circle itself and seeing the power of the circle*	Culture is Medicine	

It is important to acknowledge the subjective nature of thematic analysis and the active role that I as the researcher played in the interpretation and assigning meaning to codes. In RTA, themes are not embedded in the data waiting to be found, but instead, the researcher “must actively construe the relationship among the different codes and examine how this relationship may inform the narrative of a given theme” (Byrne, 2022, p. 1403).

Phase 4: Reviewing Potential Themes

This phase involved the careful reviewing of generated themes and the supporting subthemes and codes to ensure that they follow a coherent pattern. When discrepancies or redundancies were found, careful consideration was given to whether the subtheme needed to be re-allocated to a different theme, or a change/modification to an overarching theme should be made. The supporting theoretical framework of critical disability theory indirectly influenced this process, but was not used as a guide to create the subthemes or overarching themes, ensuring the generated themes genuinely reflected and captured the contribution of the participants without predetermined assumptions. In keeping with the dynamic and iterative nature of RTA, the themes changed drastically from the initial creation of thematic categories to the final results.

Phase 5: Defining and Naming Themes

In this phase, the codebook was closely reviewed to determine the proper allocation of codes to specific themes and subthemes. As seen in Table 1 above, In-vivo codes and subsequent generation of subthemes were used to better manage the structure of the overarching themes. The themes were then analyzed as a whole to ensure cohesiveness within and between themes.

In March of 2024, the preliminary findings and supporting data from the initial study and the secondary analysis were brought back to the research partners and community member (PD; MB, WJ) to receive feedback on the analysis. This process of ongoing community engagement and feedback throughout the research process is key to co-creating knowledge that reflects and respects Indigenous ways of knowing.

Phase 6: Producing Report

This phase involved the formal summary and write-up on the three overarching themes that emerged from the data. The themes were heavily supported by in-vivo quotes from participants to avoid misrepresentation and misinterpretation of the raw data.

Rigour

Rigour can be defined as the strength of the research design as well as the overall appropriateness of the chosen methods to answer the research question (Cypress, 2017). Rigour is a vital component of research methodology as it enhances the validity, reliability of the findings (Merriem, 2009). However, due to the subjective and at times creative nature of qualitative design, developing benchmarks for validity and reliability is challenging within a qualitative framework as the very definitions are born out of a positivistic philosophy (Whittemore et al., 2001). Because of this tension between quantitative and qualitative epistemological assumptions, Lincoln and Guba (1985) developed the following criteria for evaluating trustworthiness in qualitative research: Credibility, Dependability, Transferability, and Confirmability. It must be noted that although rigourous standards were upheld in the research process, qualitative research remains deeply subjective, contextual, and nuanced, and is often at odds with the positivistic ethos of the scientific method. The following section outlines the steps that were taken to enhance trustworthiness of the study throughout the research process.

Credibility

Credibility refers to the degree to which the participants' experiences are reflected in the findings of the study (Lincoln & Guba, 1985). In addition, credibility is enhanced by the researcher's proximity to the environment of study (Cypress, 2017). In the primary study, the credibility of the researchers lends itself to the overall rigour of the qualitative research. The focus groups and sharing circles were co-lead by Dr. Wendy Gifford who has a long-standing relationship with the community members of Pikwakanagan. In addition, the sessions were held at the Elders center and community health centers in Pikwakanagan, and a Knowledge-Keeper was present at the sharing circle to perform the ceremonial opening. Inter-rater reliability is often employed in qualitative research to enhance the credibility of the findings (Polit & Beck, 2016). In this case, ongoing collaboration between myself and Dr. Wendy Gifford throughout the analysis was helpful in the process of identifying and shaping abstract ideas and themes. In addition, the results from the primary study were brought back to the community and shared with co-investigator community member Peggy Dick, where the secondary analysis was also discussed.

Dependability

Dependability closely corresponds with the concept of reliability and refers to the stability and consistency of the research process overtime. Triangulation of data is often employed to strengthen dependability in qualitative research and refers to the methodological practice of employing diverse data sources or investigative approaches to interrogate a single phenomenon (Merriam, 2009), This strategy facilitates the corroboration of findings and yields a more comprehensive, nuanced interpretation (Polit & Beck, 2016). Triangulation of data was achieved by using different sources of data including sharing circles, focus groups, and individual interviews (n=6). The participants included cancer survivors, their family members, and community healthcare workers which enhanced the triangulation of the analysis. Finally, a thorough audit trail of the coding process was maintained on the qualitative analysis NVIVO-14 software throughout the coding process, which enhances the overall dependability of the results.

Transferability

Transferability refers to the degree to which the study findings can be transferred to another group, context, or setting (Polit & Beck, 2016). Unlike the concept of reliability in quantitative research, in qualitive research, the researcher does not claim transferability of findings, but provides detailed descriptions of the phenomenon of study to allow for the reader to assume transferability (Stalmeijer et al., 2024). By clearly demarcating my chosen theoretical framework, providing rich background of the primary study, and closely adhering to a method of thematic analysis that allowed for subjective interpretation, transferability of findings can be inferred by the reader.

Confirmability

In qualitative research, confirmability often refers to the degree to which the findings are shaped by the participants’ experiences rather than the researcher’s interpretations or personal biases (Lincoln & Guba, 1985). However, my chosen method for thematic analysis (RTA) acknowledges the subjectivity of the researcher as an inherent strength, and encourages ongoing reflexivity through an acknowledgement of positionality (Braun & Clarke, 2019). As emphasized in Braun and Clarke's 2019 framework, themes do not emerge passively from the data, and are instead constructed and shaped through the active process of the researchers engagement and relationship to the data. As such, reflexivity is deeply embedded into every step of the analysis process. I continue to reflect on my role as a settler-colonial, an academic researcher, a clinical nurse, and a cancer survivor, and try to explore how each of these unique positions contributes to the shaping of the themes I have identified within the narratives. The interpretation that I have made are in no way free of bias. My formal education and experience as a nurse working within a biomedical framework have made it difficult for me to break free from certain ontological restraints that threaten to compromise this project. Moreover, my experience as a patient within the cancer care system for over twenty years has no doubted shaped my connection to the individuals in this study, and allowed me to achieve a deeply personal understanding and interpretation of the data that would not be possible without my illness experience. Cancer has touched all our lives in some way or another. Reflecting on our personal connections to this disease and the impact it has on our loved ones is crucial for beginning to explore ways to improve the lives of cancer survivors and their families.

Chapter 5: Results

In the following section, I outline the key findings of the sharing circles, focus groups, and interviews done with the Algonquin's of Pikwakanagan First Nations community. Three key themes were crafted from the discussions of the cancer journeys within the participants:

1) Cancer Care as Colonial Machine of Debility and Slow Death.

2) Reclaiming our Lives and our Health: Self Determination Over Treatment Decisions

3) New Dimensions of Care: Thinking Outside the Biomedical Box.

Table 3 provides each theme and the supporting subthemes for each of the main themes.

Table 3

Overview of Themes and Subthemes

Main Themes	Subthemes
Cancer Care as a Colonial Machine of Debility and Slow Death	Mistrust of the Biomedical System
	Isolation and Stigma Throughout the Cancer Care Continuum
	Hard to Access Care
Reclaiming our Lives, Reclaiming our Health: Self Determination over Treatment Decisions	I Don't Want Treatment
	Spirituality is Personal
New Dimensions of Care: Thinking Outside the Biomedical Box	Integrating Western + Traditional Medicine
	Culture is Medicine
	We are all Connected (Coming Home)

Theme 1: Cancer Care as a Colonial Machine of Debility and Slow Death

In stark contrast to Western narratives that define cancer as a fight or a battle that can be conquered through dedication to treatment, an overwhelming number of participants characterized cancer as being a death sentence, a battle that is already long over before it even started. Cancer was often diagnosed at a later stage, and if treatment was an option, people were required to leave their community and travel to a larger city which came with extensive expenses, fears and anxieties of being in unfamiliar environments, and a disruption of family life on the reserve.

One participant described the overwhelming feeling of getting a cancer diagnoses and the sense of hopelessness that accompanies it:

> Because when someone's got cancer, you don't have time to be thinking, 'what am I going to do, how am I going to adapt to this, and how am I going to look after that.' You know what, when you get the news that you got cancer, everything is just out the window. Your hit and your just moonstruck. You lose all way of thinking. Because this is a disease that kills. (Participant 3, Sharing Circle)

Another participant spoke of a community member receiving their diagnosis and collapsing on the floor, and their sister being too scared to admit her diagnosis:

> I've had family members, I've had members of the community pass away with cancer. It was tough to see. I guess the hardest part was getting a family member, getting news, and hit with it so hard that they just collapsed on the floor because they thought it was the end, that they were going to lose their family member. It's the toughest point I've ever, ever had to experience. The only thing that I can remember is that I laid down on the floor beside him and talked to him, and said, "Tell me how you're feeling. Talk to me. I'm here to listen." It's important to listen to people that are going through cancer because it's a scary thing. My sister, when she found out that she had cancer, she knew she had cancer, but she was afraid to admit it. I think that's a pretty tough thing to deal with, when you get something and find out that you've got a disease that's going to kill you. You

> don't know when it's going to happen. It could happen today, it could happen an hour from now. It could happen six months from now. That's a lot of pressure on a body and on a human being, to take that news to deal with. (Participant 3, Sharing Circle)

Three subthemes emerged from the main theme *Cancer as a Colonial Machine of Debility and Slow Death*: 1) *Mistrust of the Biomedical System*; 2) *The Diagnosis as Isolation*; and 3) *Hard to Access Care*.

Subtheme 1.1- Mistrust of the System

Mistrust of the Western biomedical system echoes the decades-long history of systemic racism, acculturation, and abuse at the hands of colonial settlers (Allan & Smylie, 2015; Horill et al., 2019; Reading, 2015; TRCC, 2015). Several participants discussed the need to speak up, and stand up for themselves within the system, effectively fighting against the system that claims to be helping them. When participants discussed preparing for an appointment with their oncologist, one participant stated:

> Once you get down there and you're going through it then you're stuck in that rut and you're never going to find out anything if you don't speak up for yourself. You know, you've got to be actively involved. Don't be afraid to ask questions. Don't be afraid to question every little thing that they say to you and don't be afraid to say no if there's something that you don't want or you want done differently. You know, it's your right to know what all your options are. Those doctors, they have a protocol they follow for the treatments depending on what kind of cancer and the stage that you're at. It's like a cookie cutter thing. You know, I know I was told before they even had results back from the biopsies that,

> ‘well this is how you’re going to be treated. You’re going to have chemo, radiation and then you’re going to have brachytherapy and then the doctor walked out of the room,’ you know. No questions. No nothing. I’m sure glad he wasn’t the one that was treating me over at this hospital. But anyway. They’re not giving you choices. They’re not giving you options or anything like that and if you don’t question it, and get the information, if you don’t feel that it’s right or if you want to know more, it’s your body. It’s your health and the consequences are yours to deal with. So the choices should be yours as well. (INT 3)

When asked about who to involve in the more holistic elements of care, many participants stated that they would like someone other than a medical doctor to help them through what was viewed as the “in-between questions”:

> I was just going to say because once you’re told you have it, and then you’re going through it and you’re going to the doctor and you’re getting your medicine. You’re going through your chemo. You’re going through your radiation, and you have somebody that maybe is not family to talk you through the mental part of answering the hard questions of am I going to die. What does this mean for me. All those in between questions I think would maybe it’s not a medical doctor to be able to tell you some of this but more of a person dealing with grievance or maybe this is one thing I don’t know if there’s groups out there that do help you with it. So if there is, to have those phone numbers for those contact people to maybe, whether it be a phone or a home visit or a facility that you could go to for group counseling. (INT 2)

Several participants stated that they would rather receive care from people they knew, highlighting the importance of community-led care and Indigenous health sovereignty:

> there seems to be so much cancer over here. Like I don't know how many patients there are, but there seems to be a lot and it would be helpful if there was just one person, you know, to go to, and I think a lot of people are a lot more comfortable getting services in the community than some stranger at the Ottawa Hospital, you know. […] and it can be so much easier to deal with people that you're used to, you know. You get down to Ottawa and everybody's strangers. I mean a lot of them are so nice, like the technicians at radiation and stuff, they're really really nice people. And you get some doctors that are really nice and understanding but you get other ones that are nothing but pure assholes. (INT 3)

Themes of mistrust within the biomedical healthcare system underpinned much of the conversation surrounding treatment options and decisions. The legacy of historical colonial violence at the hands of Western healthcare providers is evident in the mistrust of healthcare professionals and their recommendations for treatment options. There is a demonstrable need to acknowledge the ongoing colonial harms and the ways in which it affects decision making at the level of tertiary cancer treatment.

Subtheme 1.2: Isolation and Stigma Throughout the Cancer Care Continuum

For many participants, cancer was viewed as a taboo subject, one that must be kept secret from family and friends, and dealt with in isolation. One participant spoke of his sister's reaction to her cancer diagnosis, and how she kept it hidden from friends and family:

> I've personally, I've dealt with this through my sister. She was just, she just laid there. She was afraid to tell people and she, when I had asked her, so I said, "It's

> okay. I know what you're going through. It's okay." And I said, she goes, "I didn't tell anybody because I thought it was just going to go away." So I only got to see her the last two weeks of her life but she dealt with the cancer by herself and she was afraid to ask questions. She was afraid to say things and it's getting them past that fear. So if this booklet was there for her in her time, and I could have helped her with whatever the book was telling me. And then this is what we're going through. These are the fears [0:05:33; unclear]. Let's face our fears together and kind of like help the patient saying this is our, this is our cancer. You're not dealing with this alone. (INT 1)

Participants spoke of feeling alone and the fear that accompanies this isolation: "And then being left alone with our thoughts. That's the hardest part. Being left alone with your thoughts is the hardest part because that's a struggle. Right, we're struggling, that's a very hard, hard thing to go through" (Participant 1, Sharing Circle). Another participant spoke of receiving their diagnosis: "Because I think the number one thing when you have disease, especially something called cancer, because it's become a taboo word, is that you feel alone" (INT 2).

The overwhelming nature of a cancer diagnosis led many participants to feel a sense of confusion, like they were unable to process the information being given to them at the time of diagnosis. This participant described the 'medical part' of it to be the most overwhelming, "I find a lot of patients come out of the doctor's, the medical part of it and just are in a brain fog and then and there's no way for them" (Participant 6, Sharing Circle). Building on the subtheme of shame, fear, and isolation, the word cancer itself brings with it a deluge of emotions that cause this disease to be highly stigmatized within

Indigenous communities. One participant stated that the moment the word is uttered in a diagnostic setting, you are unable to process any subsequent information: "most people are, once they hear the word, they leave the doctor's office, and they don't even know what happened." Many other participants spoke about the overwhelming nature of a cancer diagnosis and the difficulty in processing information: "that's overwhelming because after you hear the word cancer, you remember three things and that's it. All you think is, how am I going to survive this? You're going to hand it to somebody who has just been diagnosed with cancer and all they hear is cancer" (INT 2).

The feeling of shame also extended to the use of traditional medicines and healing rituals, and how they are typically carried out in secret or in private in the home because of the historical legacy of colonization. When asked about the use of traditional medicines, several people say they are not used. "And then the biggest factor I've seen, I haven't really seen medicines used, again, it's not something that's shared lightly. So it's usually a private and personal thing" (INT 2).

One participant spoke about their mother's embarrassment from not knowing she had cancer and therefore not being able to personalize her cancer journey with her family:

> And they did a biopsy and it was too late. It was already in the third stage and then when they found out what it was, it went through her entire body, so it reached her brain and that's what took her. But if she had known what those were at the beginning, if she had known she wouldn't have been so scared. She would have been able to tell people. One, she was embarrassed that she didn't know, so it wasn't personalized. She didn't personalize her journey. And then when I told her that you have cancer. Cancer doesn't have you. And she said it's taking me

> from this world. I said that's okay. It's okay it's taking you from this world. It's okay. I said you're going home to our Creator. (INT 1)

Many participants spoke about the early symptoms of cancer such as flu-like symptoms and stomach aches going unnoticed until the disease had progressed too far for curative treatment. One participant spoke about the fear associated with going to the doctor, and how late-stage symptoms were often downplayed out of fear:

> maybe something about getting checked out early, you know, before. Like a lot of people catch it late, right. They're just like 'oh, I just don't feel well or it's just the flu,' or it's just something, but like, you know, something that says, you know, like at these ages that you should go get checked and stuff like that that give you a little bit of knowledge about, you know, maybe signs and symptoms of not going and something that says like don't be afraid to go to the doctors and get checked out because a lot of people are just like oh well, if I don't know about it, then I don't have to worry about it. But that's not usually the case and it just gets so bad that you're kind of over your head before you ever got to start trying to deal with it. Kind of too far gone. (INT 4)

The impact of colonization remains pervasive when exploring what a cancer diagnosis meant to a family. One participant spoke about a family being reunited after the sixties scoop, only to find out that they had a late-stage blood cancer and was soon going to die:

> She had blood cancer and, but she didn't know what it was either. She thought she had a cold and she said "Oh, geez, I can't shake this cold. I can't shake this cold" and I said "have you got checked? Did you go to, ask for some cancer tests?" She goes "I'm afraid of cancer."[...] And then she goes and gets checked and she says

> yeah, you’re right. I have, and then she told me that it’s the cancer she had but it had to do with her blood cells. She goes it’s in my blood cells. They told me that I’m in stage three. So that’s how fast it happened for her. So the family didn’t have time to process this. And they’re a family that was separated by the Sixties Scoop. They were adopted out. So they just came back together, so they didn’t have a full ten years together in their elderly years. So he had a lot of anger for that. He wanted his sisters all the time. And he said I wanted her to grow old with me. But they didn’t grow up together so that they’re missing a whole chunk of life. (INT 1)

Follow-up support and monitoring for the return and progression of disease throughout the cancer care continuum was seen as lacking. Even after remission was reached, many individuals spoke about a relapsing disease of disease with no follow-up supports in place. One participant spoke of their mother who was in remission for five years before relapsing, highlighting the need for supportive care from prevention into survivorship:

> I mean I’ve known people that, you know, were told two weeks to go and all of a sudden, they’re gone already. So of course it’s more difficult to deal when you’re told to go in for a stomach ache and you’re told you’re full of cancer. So I mean there’s going to be different types of way to have to deal with this because of the progress of the cancer and the longevity or are you in remission and think you’re okay and then you get it the day after. My mom was in remission for five years and then got diagnosed again and she thought, she had no idea. So I know we don’t want to be doom and gloom but we always, you’ve still got to maintain your health and have the support even when in remission. So I think it’s a for

> everything once you're diagnosed because you're always scared it's going to come back. So it's an ongoing, you need help ongoing. (INT 2)

Subtheme 1.3: Hard to Access Care

Many participants touched on unforeseen financial cost associated with traveling to Ottawa for treatment, emphasizing the debilitating nature of cancer treatment and its impact on obtaining care. Many participants spoke of the designated lodging services for First nations people, and the limited resources provided for them:

> So whether you're going to be driving back and forth or staying in Ottawa. You know, you might feel fine and be able to drive back and forth every day. You might be able to feel fine and be able to take the medical transportation from the community here, if they're able to take you every day. But some people get a lot worse side effects and you can't travel, And that happened to me, we had to rent a place to stay down there for the whole seven-and-a-half weeks. I had the diarrhea so bad that it would have been impossible for us to drive back and forth. You know, there's the lodge at the cancer center at the Civic Hospital there, or not the cancer center, but the lodge at the Civic. Okay, but there's nowhere to cook. You can keep things in the fridge and you can heat things in the microwave, but other than that, you know, and you're supposed to be eating good healthy food while you're going through the treatments and it's not easy to do in that kind of environment. Now, they have a bus that goes back and forth to the General Hospital, you know, multiple times a day, but you've got to be well enough to get out there and wait for the bus and do the traveling and stuff and you have to check out on weekends as far as I know too. And if your side effects are really bad,

> you're going to need to rent yourself a furnished place to stay for the duration because you'd be just too damn sick to travel back and forth […] We had to pay for it. If you stay at the lodge at the Civic Hospital, that's free. There's no charge for that but if you have to rent yourself a place to stay, like for us it was like $3,800. You know, it's a lot of money and between the two of us, our cancer wiped out every dime in savings that we ever had. (INT 3)

Several participants touched on the confusing patchwork nature of beaurocratic hoop-jumping in order to receive governmental funding for medical expenses: "whether it's for insurance or for unemployment, take them and get them filled out right away so you can get those forms submitted because they take forever to start paying you anything" (INT 2). Another participant mentioned the financial tolls and stated, "our cancer wiped out every dime in savings we ever had" and, "It's thousands of dollars' worth of pills. Good god if you don't have insurance to cover that" (INT 3).

Participants spoke of the confusing and complicated nature of the treatment protocols and emphasized the difficulty of staying on track and up to date:

> If you're undergoing radiation, I don't know if everybody gets this or not, but I did. There's a lot of pills. Okay. They give you the prescription for them so you have them in advance and everything before you go down there and it's all these little packets. And there are tons of pills and it's to help with the side effects. But oh my God, they're hard, they're complicated to figure out what to take, when to take, and to time it with your appointments and stuff like that. Like it's really hard. Like some you'll take every day for however many days and other ones you'll only take on certain days and it's just, it's really hard to make up like a,

> you need to make up like a calendar or a chart or something to figure out when to take these damn pills and how much water you have to drink with them because some of them you have to have lots of fluids and stuff and it's just, it's really difficult. (INT 3)

In addition to geographical and financial barriers, several participants mentioned the technological skills required to navigate the cancer care system at the hospital, and the lack of these skills in older community members. One participant stated,

> Make sure to keep your OHIP card and your appointment card on you at all times. You have to use your OHIP card to fill in the My Symptoms Matter at the computer every week...If you don't know how to use a computer, then you need to have somebody with you to help you do that. (INT 3)

Barriers to accessing culturally safe care in the hospital setting were also touched on by multiple participants. The use of traditional medicines in First Nations healing rituals are well-documented, but many family members and survivors stated that they were unable to engage with traditional healing methods without a medical doctor's approval. One participant spoke of their doctor needing to approve of their traditional medicines: "Some examples would be too, like with the [1:33:44, unclear; Chaga] tea, we have where it was considered a traditional medicine for that person, right. And the doctor had to approve it" (INT 4). This subtheme emphasizes the complex nature of access when discussing access to cancer care and calls for additional research into identifying and addressing barriers to access for Indigenous communities.

Theme 2: Reclaiming our Lives, Reclaiming our Health: Self Determination over Treatment Decisions

Throughout the sharing circles and interviews, there were many conversations surrounding colonization, and addressing it head on unlike in the past where it has been historically and systemically ignored and repressed. There was a tone of optimistic change in the rooms, an acknowledgement of colonial harm while simultaneously feeling hopeful for a future where it's no longer necessary to hide one's culture:

> it's important to remember who we are as a person. Remember who we are as a people. Remember that we're only human and there's only so much that we can do for not only others, but for ourselves. And that's why humans rely on each other, no matter what colour we carry in our race, because the medicine wheel carries all of us. So, colonization is there, it happened, yes, we're grieving as a native people because there's a whole slew of things that we don't know. But what you know right now is who we are, what we know right now is together and feeding off each other and our knowledge will get us through these illnesses that happen. Whether it's cancer, diabetes, it doesn't matter. (Participant 1, Sharing Circle)

When asked how we can begin to break the silence of shame and fear, many participants offered that there is no need to be afraid of using traditional treatments or expressing one's culture through ritual, food, or language. One participant stated that cancer cannot be seen as a punishment, but a nature part of the cycle of life: "knowing that cancer is not a punishment. Cancer is a part of life, a part of the human body. It's part of it" (INT 2). Through this acknowledgement and acceptance of the past, and a collective effort toward healing, messages of hope and encouragement emerged from the data. Participants spoke of remission as a real possibility if there is hope among the community: “There is something called remission. The cancers that we get have a higher rate of remission and let them know that there is hope because it is the biggest thing is hope” (Participant 1, Sharing Circle).

Two subthemes help shape the main theme *Reclaiming our Lives, Reclaiming our Health: Self-Determination Over Treatment Decisions*:1) *I Don’t Want Treatment*; and 2) *Spirituality is Personal*.

Subtheme 2.1 - I Don’t Want Treatment

The taboo nature of a cancer diagnosis in First Nation communities was described as leading to social isolation and annexation from one’s community and loved ones, as well as a fear of seeking treatment or risk of being judged. Building on theme 1 (The Cancer System as a Machine of Debility and Slow Death), participants discussed their desires to decline treatment, especially those who were further on in the disease process. Participants spoke of the desire to carry on living their lives as before their cancer diagnosis because of the debilitating effect of chemotherapy and radiation. Several participants spoke about wanting to know how long they had if they decided to forgo treatment. One participant discussed his uncle’s decision to decline treatment:

> Some people are going to want to get the treatments and get the help and do whatever they can, get it cut out or however, some people are going to want that but then I mean, if you find out that you got really bad, then other people are just going to kind of accept it and… just like even my uncle, he just said, “You know, I don’t want any of this stuff.” He was already ready to go. Like he didn’t want the… he did end up doing a little bit of radiation and stuff but for the most part he was already [0:25:12, unclear] so, he was… it was just a matter of him saying it’s

> just going to be so much time and that's the time I got. He was fine with that. (Participant 5, Health Care Providers)

Another participant spoke of her experience at the Ottawa hospital discussing treatment options with her oncologist, and how she felt pressured into treatment:

> Like one of the options for me would have been, well, if I don't get any treatment at all, what's going to happen. How long am I going to have? Now that you've determined it's stage 2B, you know, what do you see happening with that if I don't go with these treatments. And there was one treatment that, that brachytherapy that I really did not want, but the doctor did talk me into it in the end. But he explained everything, you know. Well I felt better about it once I got the explanation but I sure as hell didn't feel good about it when I was told that I was getting it. You know, so sometimes it's just a matter of getting more information and to know whether you're going to be able to handle it or if you're just going to say no frigging way. You're not doing that to me. (INT 3)

Participants described the difficulty of watching loved ones undergo treatment and that effect on their own decisions to decline treatment:

> Because most people I guess stage 4 are going to look at this and be like well, I'm already basically dead. You know, a lot of them aren't going to do the chemo and the radiation and that stuff just because they've already seen it so much with family members or, you know, somebody that they know or, I think those are, you know, the main. (INT 4)

Many participants spoke about their family members declining treatment in order to spend more time with their loved ones in their community: "You know, they'd rather just live like they're living their normal life until they're gone. That seems to be most of the time the case" (Participant 2, Health Care Providers). Participants discussed the importance of respecting the wishes and decisions of the person with cancer:

> I guess it's going to be pretty well respecting the wish of the person who has the cancer on what they want to have done. They want the treatments, or if they don't, or… they just want to spend their last time with their family or things like that. (INT 6)

The subtheme *I Don't Want Treatment* highlights the deeply engrained paternalistic drivers of biomedical healthcare delivery, largely ignoring the more holistic picture of health held by Indigenous cultures.

Subtheme 2.3 - Spirituality is Personal

Spirituality for First Nations people is incredibly dynamic, complex, and varies vastly from individual to individual. The theme of individual spirituality (named *Spirituality is Personal*) reinforces self-determination in the creation of culturally safe cancer care. Many participants spoke of the dangers in assuming one's spiritual or religion affiliations:

> So that spiritual, ensuring that the spiritual is there. So as I said, and we're working, the Western medicine is working along with the traditional medicine. Putting those headings in there are spiritual. So our spiritual is everybody has a spiritual or everybody has a religion. And it's okay. There's a higher power. We all know that. But how we practice that spiritual is up to the individual. So listing, give them a little list, like would give them a little note underneath that. What does spiritual mean to you. Well, that's sort of will say well I believe in the medicine wheel or they can come around and say well, I believe in my church or I

> believe in Buddha. So they have that little something that they are putting to their spiritual. The individual is putting it to their spiritual. What does their spiritual mean to them? And then same with the mental. What does the mental, the mind, what is going through our minds right now when it comes to cancer? What is going through our minds? What is the fear. How can we dispel this fear? (INT 1)

When discussing the inclusion of culturally relevant information into the information binders, one participant discussed his mother's spiritual wishes for her funeral:

> You pretty well have to know what the person… like if they're fully into the traditional stuff. Because my mother wasn't fully into the traditional stuff. When she was going through her thing with cancer, there was one request. She wanted [Name 12] sing one song at the graveyard and that was all she wanted for the native thing. That was it. (Participant 5, Sharing Circle)

Moreover, many participants spoke about the complex dynamic of the catholic religion, especially within residential schools, and how many still chose to practice it:

> I guess it depends on what the persons [0:12:07; unclear; leaning], are they Catholic? And, because it was the Catholic church I guess that's where most of the reserves, including Pikwakanagan and residential schools were run mainly by Catholics and be best to find out from the patient what is their spiritual leaning, if any. If we try to do, we pull some Catholic, Christian [0:12:40; inaudible] may be offended or get upset because especially now after the residential schools' inquiry and the results of that, you know, I know that there are people who have changed their minds and don't want the church or the religion here. But there are some who still do […]I think you want to be careful assuming and then trying to give

> some consultation or, or some treatment, some treatment that may incorporate that and maybe offend the person and make them afraid or not willing to participate. (INT 5)

Many participants spoke to the diversity of faiths, religion, and spiritualities between and within First Nation communities in Canada:

> There's all sorts of things out there in the Indigenous religions in different First Nations and Six Nations and all through it all over Canada. So I think you would have to have your contact. Contact of the different people for each of the places and then, because they all different, they all have different beliefs and do different ritualistic things. I mean ritualist is probably not the right word to use there and I probably shouldn't have used it. But again, you can't give a lot of information on it, or maybe even get that community to do their own little booklet to add to the big booklet. (INT 2)

However, many participants do not practice Western religions that take place in a church such as Catholicism. Several participants spoke of "creator" and more traditional Indigenous spiritual practices:

> Prayers can take a second. Prayers can say thank you God. Prayers can take Creator thank you for letting me go to work and coming home safely to my family. So prayers happen on a daily. I don't need a great big cathedral to go to do my prayers. I just need me to say thank you. We say [0:14:44; Indigenous language]. So [0:14:46; Indigenous language] Creator. It takes a moment in time and then keeping that positivity in here in the mind. It's very powerful. Very powerful because then you're making amends of who you are as a person. Making

> amends with who you are and what your life cycle has taken you through. And knowing that cancer is not a punishment. Cancer is a part of life, a part of the human body. It's part of it. So how do we deal with it. How can we go through this step in a positive way to ensure that I've done everything I could, the medical's done everything that they could medically to help me with my physical. So then I start looking at my spiritual. I start looking at my mental. I start looking at my emotions. (INT 1)

For some participants, the medicine wheel and other traditional spiritual practices were viewed as essential to health and wellbeing. For others, the more traditional approaches were not used at all. One participant, separated from his family by the sixties scoop, spoke about his difficulty in engaging with the traditional way of life:

> So it's tough for me to say, you know, when she talks about the traditional medicines, I kind of have to look at her and go, well, I don't understand them and I don't understand them if they can heal me but I know… and then I was raised in the Western world. (Participant 3, Sharing Circle)

Spiritual practices were seen by all participants as individual and complex, mediated by the lived experience of residential schools, and connection with a lost culture. Self-determination over the inclusion of spiritually and culturally relevant information into biomedical literature on cancer care was viewed as extremely important.

Theme 3: New Dimensions of Care: Thinking Outside the Biomedical Box

The final theme of *New Dimensions of Care: Thinking Outside the Biomedical Box* highlights the stark paradigm differences between Western and traditional approaches to health and wellness, and calls for not only a collective, family and community-driven approach to care, but one that appreciates the interconnectivity of all things, living and dead. Three subthemes support the final theme: 1) *Integrating Western and Traditional Approaches*, 2) *Culture as Medicine*, and 3) *We are all Connected (Coming Home).*

Subtheme 3.1 - Integrating Western and Traditional Approaches

When discussing cultural safety within cancer care, the theme of integrating western and traditional approaches to cancer treatment emerged strongly from the data. Participants spoke of the two worlds 'coming together' to help the patient:

> I would just make sure that the Western society and the Native society are coming together and we're going on these journeys together now ensuring that we go hand in hand, not separated. That only the medical means that it's going to be accepted and not that the Native way of healing is not going to be accepted. Make sure that we're together and that we're accepting one another. Because I'm by far not a doctor. I'm by far not a nurse and I don't pretend to be. But I do know my spirituality. I do know my medicine wheel. I do know our connection to earth. I do know we have a higher power, Creator. So the medical society comes in and they know about the sciences. They know about cancer. They've studied it in and out where I haven't. So we're working together for the benefit of the patient.
>
> We're there for the patient. (INT 1)

Many participants spoke of hospitals and western health institutions becoming more and more accepting of Indigenous healing methods within the four walls of the hospital:

> Some examples would be too, like with the [1:33:44, unclear; Chaga] tea, we have where it was considered a traditional medicine for that person, right. And the doctor had to approve it. So, anyways, now it's become more of a practice at the

> hospital. So now, they... some of them, I had traditional medicines can I keep it, the hospital is more accepting of that. So now, it's a practice that they do at the hospitals. You know, you even [1:34:11, unclear]. So, these are things that we largely have [1:34:15, unclear] if you like, show of hands, how many people want that in there. (Participant 5, Sharing Circle)

One participant spoke of how they were able to smudge in hospital without setting the fire detectors off:

> I just wanted to mention about the smudging because a lot of people... in hospital included, there's a lot of people in Canada that like to smudge. It's the lighting of, it's the fire itself. So, what we did is we went outside, we smudged a glass and then they put a lid on the glass [1:35:01, unclear] we took the sweetgrass in, put it in my sister's hand, and then we opened up the glass with the smudge already in it, so that she still got the smudge but there was no fire. So, everybody was [1:35:16, unclear] and all the way around. So, we also did that with the sage, and we also did that with the tobacco. So, we just… and then water is water, is water. That's also a sacred medicine. So, we switched the air with just water. (Participant 2, Sharing Circle)

Several people spoke of the lingering effects of colonization, and systematic acculturation efforts whereby the western world silenced the Indigenous way of healing: "It was taken from us, the way we practiced, but today's society, with a lot of us receiving our education and a world that's evolving, we realize, the Western world realized, the traditional realized, we need to be together" (INT 1).

Although fear, isolation, and shame emerged starkly from the data when participants were asked to elaborate on their experiences within the cancer care system, throughout the sessions and interviews, it became clear that with strong family and community involvement, sharing stories and experiences, and learning about treatment options, participants were able to reclaim a sense of control over their treatment choices and their individual cancer journey. Many participants spoke of the importance of being at home, whether that is between treatments or at the end of life:

> And definitely just having like, you know, and show that there's like help and care and, you know, that they always don't have to just go and die in a hospital that they're, you know, you know, most of the people here, like that usually like to not be in the hospital so if they can have home care and then people coming in to help them and stuff to know that that's there. So I think that's a big one. (INT 4)

One participant spoke of the importance of being in one's home in order to be able to practice personal spiritual beliefs that would likely not be recognized or tolerated in a tertiary care centre:

> It's more of definitely being at home, not out of their environment. And then the biggest factor I've seen, I haven't really seen medicines used, again, it's not something that's shared lightly. So it's usually a private and personal thing. […] as I say, I think being at home is I found one of the most important things for them for their spiritual belief. […] they have their husbands. They have their children. They have visitors coming in and in a hospital setting you really can't have that. (INT 2)

Another participant spoke about the importance of being discharged from the 'Western Model' of care at the end of life and being able to die at home:

> because we have that where someone in the hospital who was being discharged from the hospital, was discharged with the Western model care and then we came in and did some discharge planning with them and they were able to come home and die. You know what I mean? That would be a really good example. From the time that they're being discharge from hospital, coming home, we had their home set up within six hours. That could be like a scenario we put in there just to show kinds of things that we do. (Participant 4, Sharing Circle)

Cancer treatment is often delivered in large tertiary care hospitals, far from the person's home, and away from family and community. There is an evident need to de-centralize and de-institutionalize cancer treatment and allow people to be treated closer to their communities or in their homes

Subtheme 3.2: Culture is Medicine

Although culture is notoriously difficult to define, engaging with traditional teachings and rituals was seen by many to be viewed as a sort of medicine in itself. Traditional medicines are an important aspect of First Nations holistic healing, but the cultural practices surrounding these medicines are considered just as important to the holistic healing process. One participant spoke of a days-long ritual wherein cedar was used for cleansing the body:

> And definitely having their cedar baths and their cleansing and the amount of days is different for some. Like it's a four-day process and again having a feast and, there's just a lot of different things that are really great for them. (INT 2)

When asked about ways to improve cancer resources for Indigenous patients, many participants spoke of smudging ceremonies and other community healing events:

> Maybe have like a medicine wheel with some sweetgrass, you know. Maybe some nicer pictures and maybe just short form it a little bit more. It might be a little bit much for, you know, some people to go through like we were talking about and yeah, maybe more, you know, traditional practices would be good too. You know whether it's smudging or even like a sharing circle or, you know, maybe for like a bunch of people that did have cancer, you know what I mean? Maybe there was like a bunch of people that have it in the community. Like they could kind of have like a sharing circle where they could be, you know, each person kind of share their experience or what their going through or maybe how to get through it better. Maybe more like knowing more traditional medicines and stuff like that. (INT 4)

Participants spoke of rituals such as sharing circles and healing circles, typically led by community elders which are seen as crucial to the healing process for First Nations communities: "Elders do ceremony. The ceremony could be, it could be the healing circle itself and seeing the power of the circle yesterday" (INT 1).

In addition to sharing and healing circles, many participants spoke about rituals surrounding food, especially traditional foods from the land. One participant spoke of the ritual wherein the family takes up a plate of food for the deceased: "I just know that when somebody passes away, they do up a plate for the spirits...Yeah, it was... when a person passes away, they do up a dish of food that they take, and they put it in the bush for the spirits" (INT 5). Another participant spoke of drinking fish broth as a child with her family, and how it had healing properties:

> he brought fish home and we made the fish broth that my sister [Name 7] couldn't drink. She wanted fish broth so bad because that's what my mother used to give us when we were kids. And he brought home fish, so we made fish broth and then we drank that, and we were thinking of my sister [Name 7] when it happened. The person that came to see us, we gave them fish broth as well, in place of my sister, we gave them fish broth. So, then we were still caring for her, caring for us, those little things that were missing. Yeah, we'd place it on someone else and they were appreciative as well, so they started feeling that connection. It's nice to go and talk to somebody, but if you don't have connection to what their going through, it's not going to mean anything. (Participant 4, Sharing Circle)

One participant spoke of a certain ritual of dying whereby doors were opened until you are called home:

> wellness is ensuring that we are all in balance with our medicine wheel and I assisted her with her spiritual journey by singing to her. I sang our traditional songs to her, the [0:05:56, unclear] song, the water song and she would open up her eyes and say, "You opened the first door." "You opened the second door." "Oh my God, did you see that? I opened the third door." And then she looked at me one last time, she said, "The fourth door is here, it opened." And then she called me mom. My mother came through me and accepted her, and she died in my arms. (Participant 1, Sharing Circle)

Engaging with the rituals and practices of one’s culture in both healing and dying stages were viewed as crucial to maintaining good health and wellness. This is important to consider when developing culturally safe policies within the hospital. Allowing Indigenous people to express their culture through small actions was seen to have a positive impact on health and the cancer journey.

With the reinvigoration and preservation of Indigenous language at the forefront of reconciliation efforts in Canada, several participants spoke of the importance of incorporating the Algonquin language into health resources:

> Maybe some, maybe some of the words could be like in Algonquin and then underneath have your English, you know. Like maybe like the main subtitles could be like in Algonquin and underneath it could have like the English version of it, hyphenated. Like My Cancer Journey. Instead of that it would be like My Journey Through Cancer and then underneath it have it written in Algonquin or have that, or have the English written, or the big part written in Algonquin and then have underneath the smaller font with the English. Definitely leading with stuff like that. […] Also kind of tries to bring back our language because it’s a lost art now. There’s not many people on this reserve that know the language, including myself. I know a little bit but not much. Where my brother, he knows a lot of the language and a lot of the prayers and, so definitely stuff like that. (INT 4)

One participant spoke of the Algonquin language being part of their DNA:

> The traditional world is always there. There’s always a little portion that they’re looking for to keep it alive even if it’s one word. Speaking the ancient Algonquin,

> I'm not surprised that you know it by heart because it's on our DNA, it's in cells. And when we pray, it's in our DNA, it's in our cells. They're ancient prayers that come out of us. They're ancient knowledge that comes out. (Participant 1, Sharing Circle)

Moreover, in addition to participants wanting to see more native language in health resources, many spoke about their own personal connection to the language, and how it exists inside them even if they aren't aware of it. "And you know what, I think it meant a lot to her because I spoke it in Algonquin, I said it in Algonquin. You know, I kind of surprised myself because I didn't think I'd remember it" (Participant 6, Sharing Circle).

Cultural knowledge and practices were seen as deeply embedded in many participants identity and holistic wellbeing, and emphasises the importance of culture even in times of great pain and struggle.

Subtheme 3.3: We are All Connected (Coming Home)

The importance of family and community in the health and wellbeing of Indigenous was at the forefront of participants stories of healing through cancer. A more holistic approach to wellbeing that encompasses not only immediate family members, but extended family and community members emerged strongly as a theme within the data. Family members are often formal caretakers and play an integral role in healing:

> when my mother was diagnosed, she did accept it, she knew what was there and she was more or less worried about us children and her husband how we were going to be able to handle it. But the family, we stuck there through the whole thing. We were the ones taking care of her. Like bathing her, making sure we go and sat with her, fed her if we had to, stayed the nights with her. And I think that

> also helped because she was a very strong lady and liked to do stuff on her own. And then, having to rely on her children to bathe her, feed her, I think it made it a little easier with her own family having to do that, instead of strangers coming in and taking care of her. (Participant 4, Sharing Circle)

It's important to note that family support is not always an immediate family member, but is often aunts and uncles and other members of the community that make up a larger mesh of support. One participant described their web of support during their journey:

> I guess that would be having the supports out there, friends, family there to help you out with everything. Me, I come from a big family of aunts and uncles, so, they were there to support. Close friends that knew my mother were there for support. Even with my mother working for the First Nations, which made the workers out there good for support for us too, some of the workers would sit there and listen to what you have to say and your feelings too. So, I'd be saying it's pretty well your community support and any other contacts out there to help you make it a little bit easier. (INT 6)

Many participants spoke of the importance of keeping the connection to their community, and not isolating oneself during periods of illness:

> That's where your community members come in. They're asked to come and spend a couple of hours with somebody in palliative, palliative care and assisting them and those assistants, they sit and they listen. They hear little things like, and keeping the person connected to their community, their family, the outside world. What's happening out there today. Oh, today I've seen this and I've seen, they're talking about their community. So it's just keeping them connected to the now.

> Keeping them connected to their families, keeping them connected to their neighbours, keeping them connected to the school bus went by on time, that kind of stuff. It's just keeping them connected to the now. So it's letting the patient know that you're still here with us. You're still alive. (INT 1)

Many participants spoke of the importance of engaging with the community and keeping the connection to other community members strong:

> having that connection and then inviting them into that connection as well, opening up a little bit and opening up that door to self-awareness and to be aware and to start accepting, to me that's what some of the services… and we do have some really excellent services here. We do have some awesome people that run those services and there's so many in the community that are just willing to bond here and to come forward as well. So, we really do have a good community. (Participant 1, Sharing Circle)

One participant spoke of the connection to her community as a way out of the anger and aloneness that accompanies a cancer diagnosis:

> even though that grieving is the denial and the anger and wanting to just lash out and be angry, but it helped me understand that life is going to continue. And it was hard, but it was easier when I came back home and Pikwakanagan was around me because all of us were here. So, it was easier for me because she passed in Windsor and when I came home, I drove home by myself, and I felt that aloneness, but when I came here, I felt my family around me. It was really awesome, it was an awesome feeling. To me, wellness is that we're together and we see each other and that we have an understanding. Even if we're angry with

> somebody, usually when somebody passes away, that anger dissipates, and we assist each other. So, even that, to me, that's wellness, the family connection in your community. It's huge. (Participant 1, Sharing Circle)

Community support for cancer patients receiving treatment, especially when separated from their community was seen as having a positive impact on the cancer care experience:

> like my mom went to the Grimes Lodge and it was basically a place to stay waiting for appointment and everybody in there had some sort of cancer. So they got together and probably the best bunch of people I ever met. You wouldn't think anybody was sick because they were all helping each other. So the group therapy of different people going through it and it was all different types of cancer. So there was no just, no two people had the same thing. So again, I think make it, if there was videos or anything like that to make it for people that can understand what they're saying and not too long-winded with just medical terminology. (INT 4)

A collective approach to health and healing was evident in following quote by a participant who spoke of cancer in the collective – our cancer, *"*Let's face our fears together and kind of like help the patient saying this is our, this is our cancer. You're not dealing with this alone" (INT 1). This powerful collective approach to health and illness highlights the interconnectedness of Indigenous people, not only to family and community, but to the earth and other surroundings:

> I'm by far not a doctor. I'm by far not a nurse and I don't pretend to be. But I do know my spirituality. I do know my medicine wheel. I do know our connection to earth. So, it's important that we remember our medicine wheel and to remember

> that all humans, all living life goes through those things, a plant has emotions, a dog has emotions, they can grieve, a plant can grieve. A tree can grieve because we're all living. Mother Earth can grieve, the air can grieve, because it's a living thing. And how many know about the ozone, it's hurting, it's grieving and we're under it. We're feeling it. (Participant 1, Sharing Circle)

Storytelling was described as a means to share information and connect to one's community. Throughout the interviews, many participants spoke of the importance of sharing their stories to break the silence of cancer and connect with community: "but aren't we storytelling people? We tell stories when we're down or sick" (Participant 6, Sharing Circle). Sharing circles were seen as a medium to share stories about cancer experiences and form connections in the community:

> Well, if you go online or anywhere else, there's lots of people with lots of stories. You know, like every time I do something promotional every month about cancer, they always have somebody's true stories, or they have how they coped with it or whatever. Maybe something like that more traditional would be okay. I don't know. Stories are nice to hear when someone is sitting beside you if you've been diagnosed with cancer, instead of oh give me a pen and paper, I'm going to write all this stuff down. No, that's not what I'm going to be reaching for. (Participant 8, Sharing Circle)

Participant 3 spoke about their experience going into people's homes and listening to the stories of cancer patients and survivors:

> What we've all heard today, we've heard some positive, we've heard some negative things. We can put them into a story, and just share. you know, I was a

> home maintenance person, I served the community, I had about 34 clients, and in those 34 clients, I probably had about five that had cancer. and a lot of the elderly, they're mostly elderly, it was… it just made me day. You know, I looked forward to getting up and getting out there and going to work and going inside these people's homes and saying, okay, well, and them saying well I don't have much work for you today. I said, well, okay, sit down, let's talk. I'll listen, talk. What's on your mind? They'd tell me a story about what happened to them in a week, or something happened in their family or something funny that would happen, but it was always enjoyment to see them laugh and share. (Participant 3, Sharing Circle)

One participant suggested story-sharing as a way to break the stigma surrounding cancer:

> Maybe stories, true life stories or something. This is all, like you said, it's all medical. I don't know, I've been around people who have received that they had cancer news, and I'm pretty sure they didn't ask me to go grab them a book about it. You know, so they can write about it. So, I don't know, if it was more, or someone can bring it to you and work with you, like a workbook, with somebody, that would be… because I don't think I would want to sit there and be like, okay, I've been diagnosed with liver cancer. I'm going to write that down. I don't think I'd want to be doing any of that. It would be nice if somebody sat beside me and helped me work with them, read stories, maybe hear little tradition things in here. You know. Coping mechanism or something. Maybe that would be more interesting to me, than any of this. (Participant 5, Sharing Circle)

Remaining at home, being surrounded by community and family, and engaging in traditional activities and healing rituals emerged as a new dimension and strength-based solution to the struggle of navigating the cancer care system.

Chapter Six – Integrated Discussion

The purpose of this study was to develop a critical understanding of culturally safe cancer care by exploring the experience of cancer survivors and their families in the Algonquin's of Pikwakanagan First Nation's community. This secondary analysis was guided by the theoretical framework of critical disability theory, specifically the concepts of debility and inclusionism as they relate to cultural safety and reconciliation. In this chapter, I discuss the results in relation to the theoretical framework and the broader research literature. I then discuss the findings in relation to the four domains of nursing practice: policy, practice, education, and research. Lastly, I discuss strengths and limitations of this study, and concluding remarks.

The overwhelming majority of participants described cancer as a death sentence. Community members felt powerless against a disease that has ravaged their communities with comments such as: "I can't even think of it because I've been given a sentence of death and I have no say in it. I have no say in it" (Participant 4, Sharing Circle). Many participants spoke of seeking healthcare for other ailments, only to be diagnosed with late-stage malignancies. These findings are keeping with the literature that demonstrates that Indigenous people are consistently diagnosed at later stages in the disease process (Bryant et al., 2021; Cancer Care Ontario, 2015; Enuaraq et al., 2021; Horill et al., 2020). The shame and isolation that accompanies a cancer diagnosis can be tied to the notion that people in some Indigenous communities view cancer as a disease of colonization, a 'white man's disease' caused by the trauma and violence of post-colonial existence (Shahid & Thompson, 2009). Moreover, the inherent mistrust of the biomedical healthcare system was a pervasive theme throughout the analysis. This mistrust dates back centuries to the early days of violent colonial practices and impacts the health decisions of First Nations people. Barriers to accessing oncology care for Indigenous people are often mediated by the structural racism they encounter within those spaces (Allen & Smylie, 2015; Brown, 2017; Gifford et al., 2022), often resulting in delayed diagnoses, untreated pain, and other unmet health needs (Kitching et al., 2020). Issues of safe and equitable access to care have been at the epicentre of discourses surrounding cultural safety within healthcare since its inception (Enuaraq et al., 2017; Horill, 2019). We understand from the literature that barriers to accessing cancer care for first nations people are widespread, complex, and systemic (Enuaraq et al., 2017; Horill et al., 2019a). Exploring first-hand the lived experience of First Nations people within the cancer care system can uncover hidden barriers to access that continue to fuel health disparities between First Nations and non-first nations peoples.

The Cancer Care System as a Colonial Machine of Debility and Slow Death

Jaspir Puar (2017) disrupts traditional conceptions of health, disability, and the governing of marginalized bodies that serve the neoliberal agenda. Disability biopolitics, specifically the ongoing process of debility in post-colonial neoliberal society, is a useful analytic lens to explore the inherent mistrust that First Nations people have of the biomedical system, and the shame, isolation, and fear of a late-stage cancer diagnosis. Puar (2017) states that “the production of most of the world’s disability happens through colonial violence, developmentalism, war, occupation, and the disparity of resources” (p. xix). Bodily injury is not only determined by societal and economic forces, but by the purposeful and ongoing subjection of certain groups of people into debilitating living conditions that result in what Lauren Berlant (2011) terms slow death, the process by which people are kept alive without improving while at the same time extracting financial and economic profit from these individuals in the face of pain, suffering, and deterioration, often masked by everyday existence (Puar, 2017). This often occurs in subtle, covert ways in which marginalized and disenfranchised communities, such as people living on First Nations reserves, experience suffering, degradation, and steady decline:

> Slow death prospers not in traumatic events, as discrete time-framed phenomena like military encounters and genocides can appear to do, but in temporally labile environments whose qualities and whose contours in time and space are often identified with the presentness of ordinariness itself. (Berlant, 2011a, p. 100)

Debility is a process by which larger societal forces purposefully engineer the circumstances for slow death (Holmes, 2020; Puar, 2017). The Algonquin's of Pikwakanagan community participants echoed processes of debility and slow death when discussing the experience of cancer within their community, describing conditions for emotional, physical, and financial debility that the biomedical system has engineered throughout the cancer care continuum. Many participants spoke of the physically debilitating nature of cancer treatment, including the negative impacts on their physical health, the financial debility of a cancer diagnosis ("cancer wiped out every dime in savings we ever had" [INT 4]), and the emotionally debilitating process of navigating a cancer diagnosis that led people to retreat from their families and friends and isolate themselves from their connections, community, and culture. These overlapping states of debility are viewed by Puar as a form of biopolitical control, not simply the byproduct of late capitalism. The debilitation of vulnerable communities is essential to upholding the greater forces of capitalist control (Puar, 2017). The system failures within the cancer care continuum are not only a result of the historical effects of colonization, but of ongoing colonial violence that is engineered to produce conditions by which Indigenous people with cancer are forced into a state of slow death where they are existing without getting better. These conditions, according to Puar (2012), serve to uphold machines of capitalism and profitability: “This revaluing of excess/debility is potent because, simply put, debility—slow death—is profitable for capitalism. In neoliberal, biomedical, and biotechnological terms, the body is always debilitated in relation to its ever-expanding potentiality.” (p. 180). The ongoing physical, emotional, and financial debilitation and incapacitation caused by the biomedical cancer care system serves to uphold regimes of colonial rule within neoliberal governance. Navigating treatment appointments, jurisdictional healthcare and the debilitating physical side effects was found to be a difficult and overwhelming process for participants and their families. Although it might be suggested, given recent medical advances, that fears surrounding cancer as a death sentence are unfounded and unreasonable, Hammond et al., (2017) notes that, “perceptions of cancer’s fatality are aligned with the typical cancer trajectory within First Nations communities in Canada, where inaccessibility and inadequacy of services across the cancer continuum lead to later stage diagnoses and more deaths” (p. 196).

Transient Capacitation - Which Lives are Worth Saving?

Capacitation of debilitated bodies refers to the process by which certain bodies are deemed ‘capable’ with the capacity of integrating into dominant society. It is a process through which government forces determine which bodies are worthy of state support, validation, and protection (Puar, 2017). Cancer Care Ontario (CCO), the provincial government’s principal cancer advisory group, is an organization whose purpose is to provide health care workers, organizations, and policymakers with the most up-to-date information on cancer knowledge (Cancer Care Ontario, 2023). The CCO guidelines emphasis personal risk factors as the cause of cancer development, stating, “Our chances of getting cancer depend on risk factors. Risk factors are facts about you, including how you live, and your personal and family history" (CCO, 2023). Through the analytic lens of Puar's capacitation, CCO's guidelines can be viewed as an attempt to capacitate people who have fewer risk factors for cancer and grant them the privileges of ableism and normativity, while ignoring the larger government apparatus, structures and processes that create and sustain the conditions that increase people's risk factors for slow death and debility. Puar (2017) discusses the concept of responsibilization, referring to the neoliberal process whereby certain groups are responsible for their own health and security in ways that often justify structural violence and perpetuate inequalities. This process helps individualize blame while absolving the state of accountability. A section of the CCO guidelines is quoted stating, "Choosing good nutrition and a healthy lifestyle can protect your DNA, counteract inherited risk factors and help reduce your risk of cancer" (CCO, 2023). This statement emphasizes the possibility of transient capacitation for those who are able to 'chose' nutritional foods, ignoring the reality that the historical processes of land annexation and dispossession has resulted in reduced access to healthy food resources, specifically traditional foods, not to mention mass deforestation, pollution, and a proliferation of industry (Elliott & Jayatilaka, 2011; Richmond & Ross, 2009). This is echoed in participant's frustration of the circumstances of housing support when coming to Ottawa for cancer treatment:

> Okay, but there's nowhere to cook. You can keep things in the fridge and you can heat things in the microwave, but other than that, you know, and you're supposed to be eating good healthy food while you're going through the treatments and it's not easy to do in that kind of environment. (INT 3)

Moreover, survivors of residential schools often report having a diet insufficient in healthy foods in addition to poor quality foods that result in food-borne illness and infections

(Mosby & Gallway, 2017). Chronic malnutrition can cause insulin resistance leading to type II diabetes later in life, predisposing one to cancer as well as other chronic diseases (Mosby & Gallway, 2017). By positioning the consumption of healthy foods as a choice, Cancer Care Ontario places the responsibility of capacitation onto the very group of people that is being debilitated by the same governmental structures and processes. Those that can rise above the conditions of debility will therefore be granted access, however temporarily, to the ableist-normative privileges of healthy living.

Reclamation of Health Through Self-Determination in Treatment Decisions

When exploring the decision process of choosing to undergo cancer treatment outside of their community, many participants spoke of their decision to decline treatment and remain at home. The decision to forego biomedical routes of treatment can be viewed as a protest against the debilitating cycle of debility and the need for capacitation through medical intervention. Refusing treatment to stay in their community could be viewed as irrational from a biomedical perspective, but instead can be seen as echoing principles of self-determination and health sovereignty in the face of a debilitating system. Participants spoke of feeling pressured into treatments they did not want, however, many also spoke about their decision not to leave their community but rather to stay with their families, feeling ready to face what was to come: “some people are going to want that but then I mean, if you find out that you got really bad, then other people are just going to kind of accept it and… just like even my uncle, he just said, ‘You know, I don’t want any of this stuff.’ He was already ready” (Participant 5, HCP). The expression of these emotions highlights the deeply engrained paternalistic drivers of biomedical healthcare delivery which largely ignore the more holistic picture of health held in Indigenous cultures. The statements by participants expressing a desire to forgo treatment stands in stark contrast to the

Western understandings of human life needing protection at all costs, specifically through state-mediated interventions. Furthermore, it offers an alternative to the engineered circumstances of slow death and debility.

The decision to stay home and not pursue treatment aligns with the paradigm of health and personhood being intimately tied to culture, community, and land, and highlights self-determination as a key factor in determining what culturally safe care is. Participants echoed the push to decentralize cancer care—bringing it closer to communities—and to shift its focus away from merely sustaining life while perpetuating conditions of debility and slow death, as described by Puar, expressing a desire to remain in their communities or return home to die. One participant spoke of the importance of being at home as important for their spiritual healing: "as I say, I think being at home is I found one of the most important things…for their spiritual belief, their journey" (INT 2). There is an evident need to de-centralize and de-institutionalize cancer treatment to better align with First Nation community values of interconnectivity and holistic wellbeing (Gifford et al., 2023).

The Incommensurability of Cultural Safety in Cancer care

Cultural safety is defined in the literature as a transformative approach to healthcare that recognizes and respects Indigenous identity while acknowledging ongoing systemic harms that have led to pervasive health inequities (Allan & Smylie, 2015; Reading, 2009; Tremblay et al., 2023). By applying a lens of critical disability theory to the current state of cancer care, large gaps in care as well as insidious approaches to achieving cultural safety become visible. Tuck and Yang (2012) discuss the notion of settler-led decolonization efforts as inherently incommensurable with Indigenous ontologies, epistemologies, and cosmologies. This tension between settler and Indigenous ways of knowing effectively transforms decolonization and reconciliation efforts into symbolic metaphors that serve to alleviate settler guilt (Tuck & Yang, 2012). For example, the ethos of a patient-centered approach to health mirrors an individualistic, Western approach to healthcare, largely ignoring and dismissing the Indigenous conception of health as holistic and inextricably linked to land, community, and culture (Chiefs of Ontario et al., 2017; Gifford et al, 2023). The dominant ethos of patient-centered care held by Western institutions ignores deep-rooted conceptions of family and community as essential for healing as held by the people of Pikwakanagan. In a similar study, family was viewed by members of Pikwakanagan as "a complex network of people, relations, and connections that do not correspond to settler conceptualizations of the nuclear family" (Gifford et al., 2023, p. 389). In this study, a participant described the interconnectivity of the person and the land through the shared experience of grieving:

> So, it's important that we remember our medicine wheel and to remember that all humans, all living life goes through those things, a plant has emotions, a dog has emotions, they can grieve, a plant can grieve. A tree can grieve because we're all living. Mother Earth can grieve, the air can grieve, because it's a living thing. (Participant 1, Sharing Circle)

These conceptions of health and personhood that are inextricably linked to culture, community, and land stands in stark opposition to Western narratives of a patient-centered approach to health and wellness (Gifford et al., 2023). For Indigenous people, land is seen as more than merely a physical space. It is where ceremonies are held, traditional medicines are harvested, and spiritual connections are fostered (Coulthard, 2010; Kermoal & Altaminer, 2016). The displacement and relocation of participants for the purposes of cancer treatment echoes the forced displacement of Indigenous peoples by the Canadian government for the purposes of resource extraction and settlement (Thompson, 2022). These findings highlight the stark paradigmal differences between Western and traditional approaches to health and wellness, and calls for not only a collective, family and community-driven approach to care, but one that appreciates the interconnectivity of all things, living and dead

Inclusionism and Canada's Project of Reconciliation

Since the 2016 release of the TRCs 94 Calls to Action for reconciliation, there have been growing efforts to 'decolonize' nursing and medical education (TRC, 2015). Public awareness of the historical injustices faced by Indigenous people has positioned Indigenous health at the forefront of political discussions on health equity in Canada (Horill et al., 2021). Similar to Puar's concept of capacitation, efforts to create a culturally safe environment can be critiqued through the application of Mitchell and Snyder's concept of inclusionism - the idea whereby certain individuals from a marginalized group are granted access into neoliberal forms of inclusion (and all the benefits that accompany such citizenship) insofar as it "does not demand an excessive degree of change from relatively inflexible institutions, environments, and forms of belonging" (Mitchell & Snyder, 2015, p. 14). Mitchell and Snyder describe these debilitated bodies as reinvigorated to promote neoliberal agendas, but existing on the margins of culturally inculcated norms (Mitchell & Snyder, 2015; Puar, 2017), labelling these bodies as occupying space of peripheral embodiments. According to Mitchell and Snyder, those occupying peripheral embodiments "cannot be adequately accommodated even under the most liberal, fluid, and flexible diversity doctrine given the in-built limits of community infrastructure, reasonable tolerance, limited economic resources, and traditional historical expectations about who will share the rapidly dwindling commonwealth represented by public and private spheres" (Mitchell & Snyder, 2015, p. 14). This concept of inclusionism as a critique of reconciliation and cultural safety is mirrored in the participants perceptions of their culture and beliefs within western biomedical healthcare. One participant spoke of the varying beliefs in traditional medicines and the diverse nature of spirituality within First Nations communities:

> You pretty well have to know… like if they're fully into the traditional stuff. Because my mother wasn't fully into the traditional stuff. When she was going through her thing with cancer, there was one request. She wanted [Name 12] sing one song at the graveyard and that was all she wanted for the native thing. That was it. (Participant 5, Sharing Circle)

A one-size-fits-all approach to the development and creation of culturally safe cancer care fails to integrate the complexities of Indigenous beliefs, and ways of knowing, living, and healing (Beckett et al., 2021), and echoes a rigid inclusionism approach to reconciliation that ultimately perpetuate and uphold cycles of debility and incapacitation.

Indigenous scholar Glen Coulthard (2014) argues that the politics of recognition in Canada have replaced former politics of acculturation and assimilation. Recognition, he argues, does little to fundamentally change the inequities present within our societal structures, and instead, is systematically employed to rehabilitate neo-colonial discourses and reinforces existing power structures (Coulthard, 2014). Recognition does not mean decolonization, but instead has resulted in the continued "dispossession of Indigenous Peoples of their lands and self-determining authority" (Coulthard, 2014, p. 25). Coulthard discusses the notion of mutuality as a required prerequisite for true emancipation and structural change, and notes that mutuality is seriously lacking in discourses surrounding decolonization and self-determination for Indigenous people. Instead, Indigenous people are sustained in a state of debility that represents more a Hegelian master-slave relationship. Coulthard's (2014) politics of recognition directly echoes the concept of inclusionism as brought forth by disability theorists such as Puar (2017), and Mitchell and Snyder (2015). Neo-colonial efforts of Indigenous inclusion in state-driven narratives fundamentally ignore the need for true institutional and structural change. First Nation's Haudenosaunee author Alicia Elliot (2019), narrates first-hand how ablenationalism is enacted through reconciliation:

> Apparently, we were to be tolerated only in a very specific context. We could entertain them in the summer and pose in photos with their children, sure, but attempting to assert sovereignty over our lands elicited moral outrage on par with drowning kittens. Maybe if we'd worn powwow dresses and brought a drumming group, they'd have been more receptive. This seems to be the preferred image of Indigenous people. Not the modern native girl in a sweatshirt and jeans trying to figure out how she fits in 'Reconciliation© Canada'. No. They want the 'genuine artifact': the stoic Indian man decked out in beads and leather, who has not one ounce of white blood because that would taint his authenticity. (Alecia Elliot, 2016, p. 152)

Reconciliation as a neoliberal human rights-driven movement can be critiqued through the lens of capacitation, inclusionism, and ablenationalism as a means to capacitate certain Indigenous people for the sake of progress, while continuing to debilitate the majority of the population. Cultural safety as the dominant framework for equitable cancer care must be understood through the same lens to ensure we are not simply echoing inclusionist approach to addressing cancer disparities.

Championing Indigenous Epistemologies Through a New Dimension of Care

When discussing cultural safety within cancer care, the theme of integrating Western and traditional approaches to cancer care and treatment emerged strongly from the data: "I would just make sure that the Western society and the Native society are coming together and we're going on these journeys together now ensuring that we go hand in hand, not separated" (INT 1). This approach echoes the concept of "Two-Eyed Seeing," first developed by Mi'kmaq elder Albert Marshall, that champions both Indigenous and Western ways of knowing the world, and values both perspectives equally to co-create new knowledge together (Bartlett et al., 2012; Poirier et al., 2023). In Two-Eyed Seeing, each paradigm provides valuable and legitimate understandings, and knowledge is located in a both/and perspective rather than an either/or perspective (Bartlett et al., 2012). Although two-eyed seeing has been at the forefront of cultural safety in healthcare, it is important to note that integrating Indigenous ways of knowing into a biomedical system while continuing to uphold a hierarchy of knowledge that places Western knowledge above Indigenous ways of knowing continues to perpetuate colonial harms (McFadden et al., 2023). Integrating traditional Indigenous and Western ways of healing in a way that is respectful of both epistemologies is difficult, and involves a deep acknowledgement of the paradigmal differences between the two knowledge systems (Broadhead & Howard, 2021). Having a desire to learn about different ways of healing, and connecting respectfully with knowledge keepers of both paradigms was viewed as a healthy step forward in culturally safe care.

Storytelling has been viewed for centuries as the primary way in which knowledge is shared and passed down among First Nations communities (Bolton et al., 2023). Storytelling has a rich history in First Nation's communities that involves honouring traditional knowledge practices and fostering relational practices that connect people with the land and cultural history (Rieger et al., 2020). Storytelling is seen as reflective of Indigenous ontologies and epistemologies including assumptions of the multiplicity, holism, and a sense of belonging and responsibility to the earth (Caxaj, 2015; Kovach, 2020). Study findings demonstrated that participants viewed storytelling played an essential role in de-stigmatizing a cancer diagnosis, and encouraged sharing among members of the community:

> Stories are nice to hear when someone is sitting beside you if you've been diagnosed with cancer, instead of oh give me a pen and paper, I'm going to write all this stuff down. No, that's not what I'm going to be reaching for. (Participant 8, Sharing Circle)

Storytelling is viewed as a powerful form of colonial resistance, and can serve as a rich tool for indigenous self-determination (Caxaj, 2015; Rieger et al., 2020). The use of storytelling to share a new diagnosis and gather information concerning navigating the cancer care system provided valuable insights on ways to de-stigmatize cancer for First nations communities and promote self-determination.

Finally, the reinvigoration and preservation of Indigenous language has been at the forefront of reconciliation efforts in Canada (TRC, 2015). Many Indigenous languages do not have a word for cancer (Canadian Partnership Against Cancer, 2014), emphasizing the stark divide between Western and Indigenous perspectives. Indigenous languages are verb-based, and emphasize the spatial interconnectedness of human, animals, and the land (Mashford-Pringle & Shawanda, 2023). These languages hold within them values and beliefs of holistic relationality, and exist in stark contrast to western anthropocentric language. Incorporating the Algonquin language into cancer resources was viewed by participants as an important way to connect with one's spirituality and culture:

> The traditional world is always there. There's always a little portion that they're looking for to keep it alive even if it's one word. Speaking the ancient Algonquin,

> I’m not surprised that you know it by heart because it’s on our DNA, it’s in [our] cells. (Participant 1, Sharing Circle)

Puar discusses language through Gayatri Spivak’s work of the subaltern stating that,

> language can enter multiplicity, and it can also be resituated as one intensification of a bodily capacity, one manner of many that the body can articulate itself, on platform out of many through which politics can enunciate, and finally one kind of matter. (Puar, 2017, p. 27)

When viewed through the context of colonial violence, debility, capacitation, giving voice to the subaltern who is “mute” serves as a means of transient capacitation through representation without systemic change.

Nursing Implications

Policy

The findings from this study emphasized that certain healthcare policies such as the engagement with healing rituals such as smudging in the hospital setting remain controlled and policed by physicians and healthcare workers, resulting in a marginalization and oppression of Indigenous ways of knowing and healing. Moreover, policies including the Medical Transport policy for First Nations people to access medically necessary health services is often acknowledge as complicating access to cancer care services, is often denied in the context of cancer prevention and screening, and applies only to the individual, failing to consider the importance of family and community when travelling for care (Horill et al., 2020; Lavoie et al., 2015; 2016). Literature surrounding culturally safe policy making emphasizes the need for a collaborative approach to policy development that respects and champions Indigenous knowledge and values (Drieger et al., 2013; Solomon et al., 2022). Involving elders and traditional healers in policy decision-making and implementation to ensure policies are rooted in cultural values and community needs helps to narrow the gap between western biomedical practices and models of traditional healing (Allen et al., 2020).

Although policies surrounding cancer care for First Nations people through organizations including the Canadian Partnership Against Cancer and CCO, larger sociopolitical action that champions policies of self-determination for First nation people are likely to have a trickle-down effect on the overall health and wellbeing of First Nations peoples. As part of the policy changes needed to improve the services and ultimately the health and wellbeing of First Nations people, the First Nations Health Transformation Agenda (FNHTA) was created in 2016 in collaboration with the Assembly of First Nations Chiefs Committee on Health, to help draw attention to jurisdictional ambiguities including issues of access, availability, and funding for cancer care and treatment (Assembly of First Nations, 2017; Beckett et al., 2021). Ongoing work is needed for policy changes in partnerships with First Nations people that uphold First Nations values and ways of knowing and being.

Practice

As the largest body of healthcare providers in Canada, nursing practice sits at the nexus of individual relational care and broader institutional structures (Horill et al., 2022). Working in collaboration with interdisciplinary team members, oncology nurses are often the first people patients encounter after a cancer diagnosis, and play a significant role in helping patients navigate the system (Horill et al. 2018, 2019; Gifford et al., 2022). Despite this, nurses often feel powerless to meet Indigenous patients' needs due to the overwhelming forces of the Western biomedical system that underpins Canadian healthcare (Horill et al., 2021; Rand et al., 2019). Nurses are educated in a deeply biomedical pedagogical paradigm and can be complicit in perpetuating assumptions that reinforce structural racism (Bourque-Bearskin et al., 2020; Horill et al., 2019) and must look critically at the social structures and relations of power that underpin the system in which we operate.

Well-documented incidences of structural racism continue to permeate the healthcare system and negatively impact the perception of cancer care as perceived by First Nations people (Allan & Smylie, 2015; Browne et al., 2016; Gifford et al., 2019a, 2022). Nurses must recognize that Indigenous people living with cancer have a different and unique understanding of health and illness and a unique approach to healing (Beckett et al., 2021; Enuaraq et al., 2021; Gifford et al., 2022). McGibbons and Lukeman (2019) state that nursing has seen a "resurgence of the political, a deliberate focus on social change, and a growing uneasiness with remaining neutral in the face of such pressing need" (p. 3). Although cultural safety remains the dominant framework for the decolonization of cancer care, caution must be used to avoid a performative level of inclusion and recognition without a commitment to deep, systemic change. A study exploring oncology nurses' perspectives on access to cancer care for Indigenous peoples, Horill et al. (2022) found that although nurses attempted to integrate culturally safe and trauma-informed care into their practice, they often felt constrained by biomedical discourses, making it challenging to address relational aspects of care. Through a radical reframing of the nursing biomedical understanding of health and disease by exploring First Nations experiences in the cancer care system, nursing practice can be reshaped to reflect a more holistic approach to cancer care.

A growing number of nurses and regulatory bodies are joining the movement to combat Indigenous racism in healthcare. For example, in 2021, the Canadian Nurses Association (CNA) released A Nursing Declaration Against Anti-Indigenous Racism in Healthcare, a statement acknowledging that racism in healthcare is a national crisis with historical roots in colonization, and commits nurses to specific actions including policy and practice reviews, as well as culturally safe training and advocacy. In terms of actionable frameworks to address Indigenous racism at the practice level, Indigenous nurse Holly Graham developed a framework for practicing nurses to recognize, identify, and intervene when racist behaviour is encountered in the workplace. Her framework, titled CPR-RACISM, encourages a speak-up culture in the workplace, and reinforces the delivery of safe, ethical, competent, and trauma-informed nursing at the level of practice (Graham, 2024).

Education

There has been a galvanize interest in improving the educational preparedness of undergraduate nurses regarding the health of Indigenous people (Drummond, 2020; TRC, 2015). The TRCs Calls to Action (2015) emphasizes the need for faculties of nursing education to include Indigenous health issues and perspectives into their curriculums. However, deep ontological and epistemological tensions exist between Indigenous ways of knowing, and biomedical nursing education which relies heavily on empirical ‘evidence-based’ pedagogy. (Drummond, 2020; Moreton-Robinson, 2016). The inherent incommensurability of these knowledge systems must be explored to ensure that Indigenous knowledge is not simply filtered through a Western epistemological lens (Drummond, 2020).

In 2025, the CCO launched the online Indigenous Relationship and Cultural Safety (IRCS) courses to provide skills-based training in cultural competency, conflict resolution, human rights and anti-racism to nurses working with Indigenous Services (Rand et al., 2019; TRC, 2015). Although the course was viewed as helpful in increasing knowledge about Indigenous people, the course content fails to address the active and ongoing role that nurses play in perpetuating structural colonial violence. Studies demonstrate that incorporating Indigenous perspectives into academia is usually limited to a single course or module, failing to challenge or address underlying discourses of colonialism, racism, and ongoing institutional violence (Blanchet–Garneau et al., 2021). The Aboriginal Nurses Association of Canada (ANAC) highlights the need for nursing students to reflect on their own personal biases, and to recognize and criticize the power imbalances that shape our healthcare system (ANAC, 2009), emphasizing the importance of reflective practice in nursing education. To support reconciliation and decolonization within the profession, nursing students must begin by acknowledging the harmful colonial legacies of the profession which directly impact the health of Indigenous peoples, and work to dismantle Western epistemological understandings of health and disease that perpetuate colonial power imbalances. The Canadian Federation of Nurses Union (CFNU), the largest organization representing nursing students and frontline unionized nurses released a report advocating for nursing curricula to include Indigenous perspectives, histories, and knowledge systems while acknowledging the harmful legacy the nursing profession has left in its wake. The report also advocated for universities to partner with Indigenous communities and Knowledge Keepers to build curricula that honours and respects Indigenous knowledge systems (CNFU, 2025).

Research

Indigenous health research conducted from a biomedical perspective is often poorly aligned with community values and worldviews of Indigenous people (Hammond et al., 2018; Hyett et al., 2018; Smith, 2012). Indigenous research tends to adopt a pan-Indigenous perspective, largely ignoring unique values, beliefs, and worldviews of differing communities (Kovach, 2020; Smith, 2012). Moreover, A legacy of historical atrocities wherein medical research was performed on Indigenous peoples has eroded trust between researchers and participants within Indigenous communities (Mosby, 2013). Research with Indigenous communities requires fostering authentic trusting relationships wherein community members determine what information is relevant and useful (Gifford et al., 2021). Furthermore, research with Indigenous communities should champion Indigenous epistemologies including oral storytelling, relationality, and interconnectedness of land, language, and community (Kovach, 2020). However, despite galvanized interest in incorporating Indigenous methodologies and methods into academic research, Indigenous researchers continue to face pressure to prove these methodologies rigorous and credible by Western standards, further marginalizing, distorting, and invalidating indigenous research (Hyett et al., 2018; Saini, 2012). A decolonizing approach to research with Indigenous communities calls for innovative research methodologies that resist colonial power dynamics and knowledge subjugation (Hammond et al., 2018; Kovach, 2020). Creative research methods involving arts-based practices such as photovoice, dance, beading, and digital storytelling has demonstrated to be an effective way to foster trusting relationships and champion Indigenous knowledge systems: "ABM (Arts-Based Methods) provided opportunities to address historical issues of power difference and mistrust between researchers and Indigenous communities whose knowledge has often been exploited, discounted, and erased within research" (Hammond et al., 2018, p. 271).

Ultimately, developing Indigenous research practices requires the co-creation of "...shared spaces that legitimize Indigenous knowledge, acknowledge the tainted history of research with Indigenous Peoples, and recognize the inherent rights of Indigenous Peoples to self-determine knowledge for understanding the world" (Gifford et al., 2021, p. 7044). Developing research methodologies in collaboration with community members and encouraging community members to be co-researchers and leaders is essential in developing research methodologies in-line with Indigenous worldviews (Kovach 2020). Non-Indigenous researchers must recognize the systemic racism embedded into research institutions, acknowledge the ongoing harms of imposing Western ideology on Indigenous knowledge systems, and commit to fostering authentic and trusting relationships with Indigenous people and communities throughout the research process.

Strengths and Limitations

Strengths

The inherent strength of this study was its qualitative design which allowed for a deep and rich exploration into community members' lived experiences. As a member of the research team for the primary study, I was present at the sharing circles and focus groups which allowed for a unique understanding of the coding experience that allowed me to capture subtle emotions that might otherwise have been overlooked. Furthermore, ongoing community engagement with the Algonquin's of Pikwakanagan community throughout the writing of this thesis underscores the importance of respectful and collaborative research partnerships with Indigenous communities. Peggy Dick, an RN and co-investigator of the primary study, was integral in maintaining a connection to the people of Pikwakanagan throughout the study, and developing themes from the data that were consistent with the stories shared throughout the study.

Another strength was the compatibility of the research questions with the purpose of the primary study. This allowed for the participants to share rich perspectives on their experiences with cancer care for a deep analysis without further burdening of participants.

Limitations

Although several strengths underscore this study, the most crucial being its closeness to First Nations experience in the cancer care system, several limitations must be acknowledged. One limitation of this thesis is the lack of using an Indigenous theoretical framework. The chosen theoretical framework does not include an Indigenous perspective on health equity or disability, which allows for a limited integration of Indigenous ontological and epistemological perspectives. Furthermore, as the sole author of this thesis and of settler-colonial descent, it was not possible for me to approach this study through an Indigenous lens, omitting contextual lived experiences and potentially perpetuating epistemological hierarchies of knowledge within academia that favour Western thought. Finally, although this study provided rich exploration into the experience of cancer care for the Algonquins of Pikwakanagan First Nations community, the insights drawn may not be transferrable to other First Nation or Indigenous communities, as each community carries their own unique set of values, beliefs, knowledge and nuanced worldviews.

Conclusion

The Algonquins of Pikwakanagan First Nations community members' experiences within the cancer care system were explored in this study. This secondary analysis explored the rich stories of cancer survivors and their families navigating a violent system that disempowered and displaced them from their communities. Guided by the theoretical framework of critical disability theory, specifically the concepts of debility, capacity, and inclusionism, this thesis provides critical insights into the deleterious effects of the cancer care system, and the harmful ways in which cultural safety is enacted in the age of neoliberal reconciliation. The Canadian healthcare system has long since proven to be a site of maintained government-sanctioned colonial violence. Through the application of Puar’s concept of sanctioned maiming and debilitation, the cancer care system becomes a prolific site for the purposeful and systemic practice of debilitation to uphold current power structures. Through the application of reflexive thematic analysis, three themes emerged from the data: 1) *Cancer Care as a Colonial machine of Debility and Slow Death, Reclaiming our Lives,2) Reclaiming our Health,* and *3)New Dimensions of Care: Thinking Outside the Biomedical Box.*

The insights drawn from this study reveal not only the harmful ways in which neoliberal ableist frameworks for the delivery of cancer care continue to perpetuate health disparities and ignore the holistic needs of Indigenous peoples experiencing cancer, but the ways in which a new system of care could be imagined. There is a pressing need to draw upon the experiences of First Nations people living with cancer to critique the current healthcare system and shift the understanding of what constitutes culturally safe cancer care. For the Algonquins of Pikwakanagan First Nations, unsafe cancer care exists on many levels including limited geographical and cultural access, financial and bureaucratic barriers, and an overemphasis on the biomedical model of care. By amplifying the voices of this community, it became evident that culturally safe cancer care was severely lacking, and a desire to be treated in their communities by their community members was evident. Collectively, the findings from this study have direct implications for the nursing profession across multiple domains of policy, practice, education, and research. While cultural safety may be a step in the right direction for the nursing profession to better acknowledge the legacy of ongoing colonial violence experienced by Indigenous people, it is not enough to merely integrate a patchwork of cultural elements into pre-existing biomedical frameworks of care.

This thesis does not provide solutions to the problem of Indigenous health inequity. What I hope that it will contribute is an invitation for nurses and healthcare workers to engage in critical discussion concerning the mechanisms through which structured violence is enacted in our everyday lives and embedded in the systems in which we work. It is my hope that this study will contribute to a growing body of research that seeks to champion Indigenous knowledge systems and promote the holistic health and wellbeing of Indigenous peoples living through cancer.

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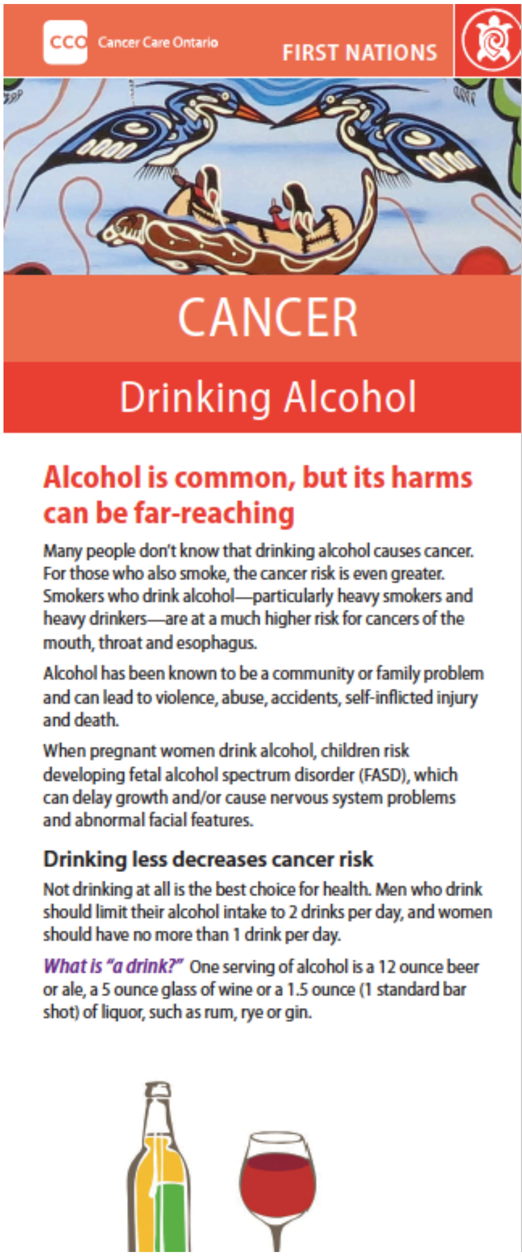
Appendices

Appendix A: Cancer Care Ontario Alcohol and Cancer Resources for First Nations



CCO Cancer Care Ontario FIRST NATIONS

CANCER

Drinking Alcohol

Alcohol is common, but its harms can be far-reaching

Many people don't know that drinking alcohol causes cancer. For those who also smoke, the cancer risk is even greater. Smokers who drink alcohol—particularly heavy smokers and heavy drinkers—are at a much higher risk for cancers of the mouth, throat and esophagus.

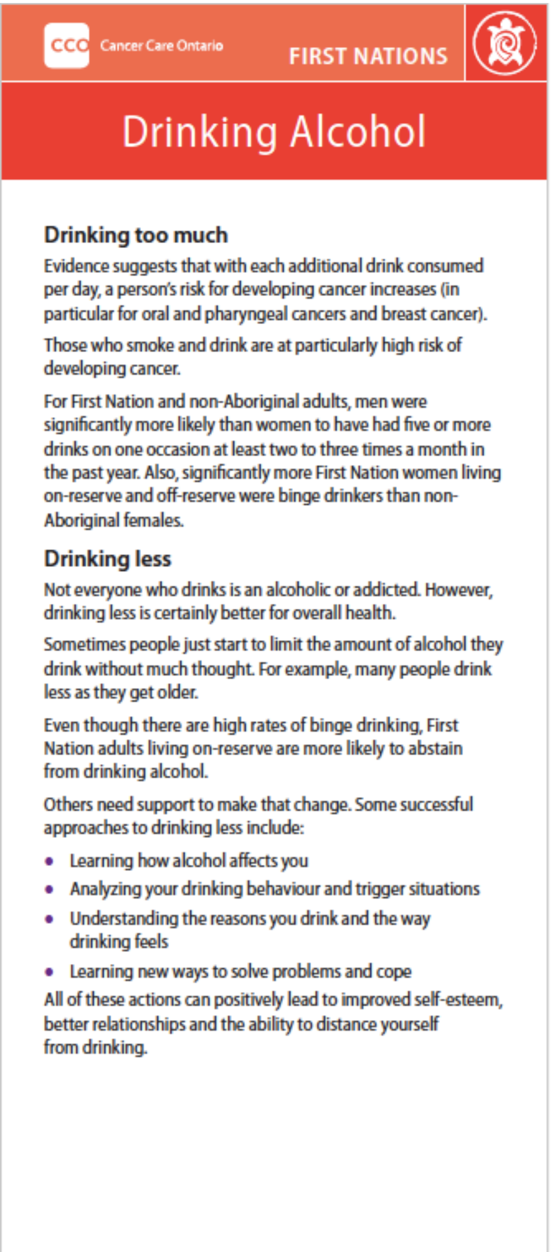
Alcohol has been known to be a community or family problem and can lead to violence, abuse, accidents, self-inflicted injury and death.

When pregnant women drink alcohol, children risk developing fetal alcohol spectrum disorder (FASD), which can delay growth and/or cause nervous system problems and abnormal facial features.

Drinking less decreases cancer risk

Not drinking at all is the best choice for health. Men who drink should limit their alcohol intake to 2 drinks per day, and women should have no more than 1 drink per day.

What is "a drink?" One serving of alcohol is a 12 ounce beer or ale, a 5 ounce glass of wine or a 1.5 ounce (1 standard bar shot) of liquor, such as rum, rye or gin.



CCO Cancer Care Ontario FIRST NATIONS

Drinking Alcohol

Drinking too much

Evidence suggests that with each additional drink consumed per day, a person's risk for developing cancer increases (in particular for oral and pharyngeal cancers and breast cancer).

Those who smoke and drink are at particularly high risk of developing cancer.

For First Nation and non-Aboriginal adults, men were significantly more likely than women to have had five or more drinks on one occasion at least two to three times a month in the past year. Also, significantly more First Nation women living on-reserve and off-reserve were binge drinkers than non-Aboriginal females.

Drinking less

Not everyone who drinks is an alcoholic or addicted. However, drinking less is certainly better for overall health.

Sometimes people just start to limit the amount of alcohol they drink without much thought. For example, many people drink less as they get older.

Even though there are high rates of binge drinking, First Nation adults living on-reserve are more likely to abstain from drinking alcohol.

Others need support to make that change. Some successful approaches to drinking less include:

- Learning how alcohol affects you
- Analyzing your drinking behaviour and trigger situations
- Understanding the reasons you drink and the way drinking feels
- Learning new ways to solve problems and cope

All of these actions can positively lead to improved self-esteem, better relationships and the ability to distance yourself from drinking.

Appendix B: Inclusion/Exclusion Criteria

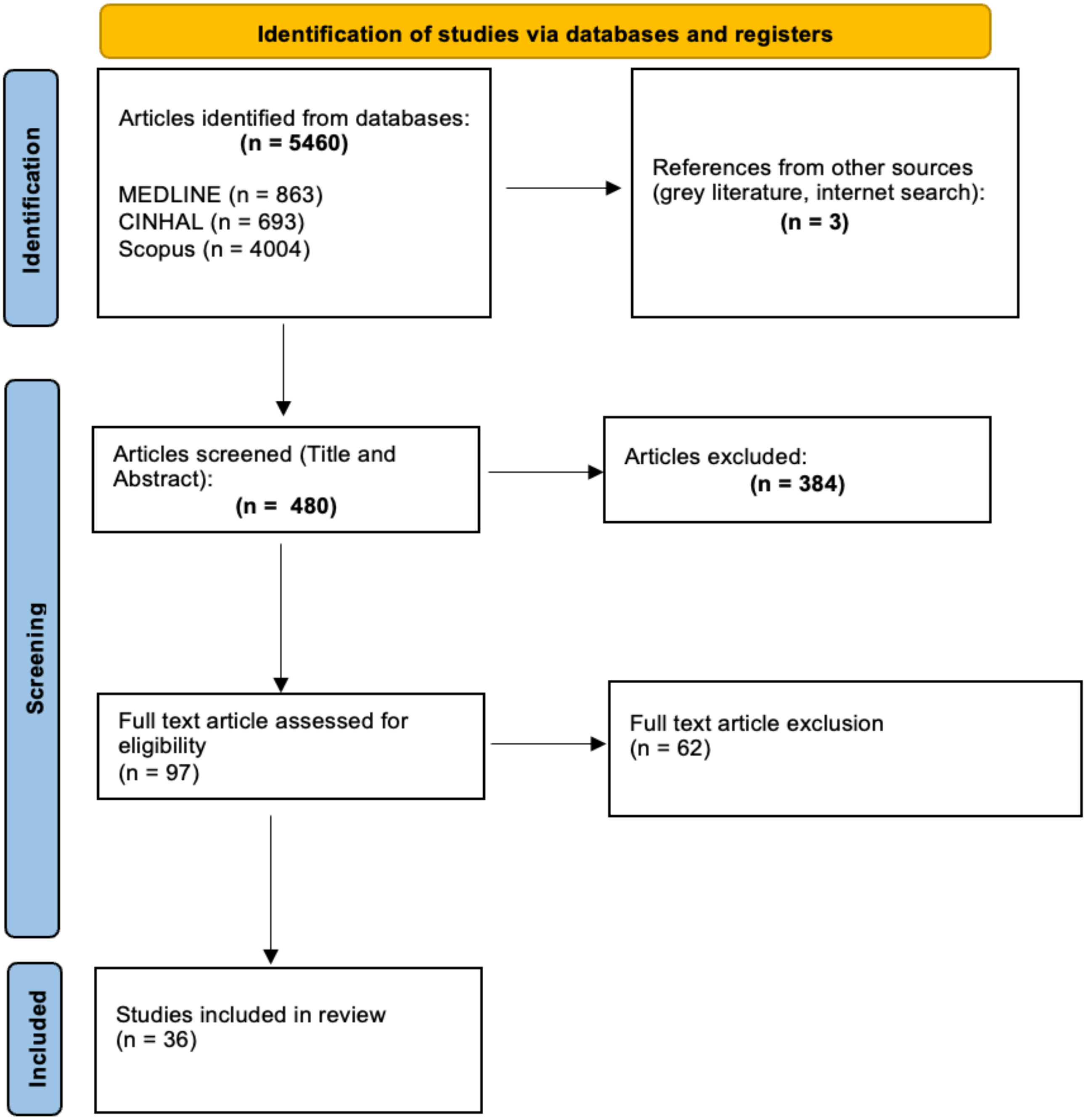
Inclusion	Exclusion
• Qualitative, quantitative, meta-analysis, systematic reviews, scoping reviews • Published between 2015-2023 • Peer-reviewed & Grey Literature • Focus on Indigenous cancer care • Full text available in English • International studies accepted	• Published before 2015 • Languages other than English • Articles that did not describe Indigenous experience with cancer care

Appendix C: Literature Search Strategy

Source	**Specific criteria relevant to search strategy**	**Total Number of Documents**	**Number of Documents meeting inclusion Criteria**
Medline (Pubmed) Accessed through uOttawa library services	Limits to all searches: English, available in full-text online	863	24 After abstract review
	S1 Indigenous OR aboriginal OR Indigen* OR Aborigin* OR "First Nations" OR Inuit OR Métis OR native AND cancer OR oncology OR neoplasm OR malignancy OR "cancer care" OR cancer* OR oncolog* OR neoplas* OR tumo?r OR malignan* OR carcino* chemotherapy OR "palliative care" OR survivorship		
	S2 “cultural safety” OR “culturally safe” OR “cultural* OR experience OR perspective OR barrier* OR access OR satisfaction OR “"patient journey" OR narrative Previously listed Inclusion criteria		
CINAHL (Ebsco) Accessed through	Indigenous OR Aboriginal OR First Nation/Métis/Inuit OR Native AND ‘Cultural safety’ OR ‘Culturally safe care” AND	693	8 After abstract review and removing

uOttawa library services	cancer OR oncology OR neoplasm OR malignancy OR "cancer care" OR cancer* OR oncolog* OR neoplas* OR tumo?r OR malignan* OR carcino* chemotherapy OR "palliative care" OR survivorship Previously listed inclusion criteria		duplicates from Medline
SCOPUS Accessed through uOttawa library services	Indigenous OR Aboriginal OR First Nation/Métis/Inuit AND 'Cultural safety' OR 'Culturally safe care" AND cancer OR oncology OR neoplasm OR malignancy OR "cancer care" OR cancer* OR oncolog* OR neoplas* OR tumo?r OR malignan* OR carcino* chemotherapy OR "palliative care" OR survivorship Previously listed inclusion criteria	4004	4 After abstract reviewing and removal of duplicates from CINAHL and Medline
World Wide Web	The following websites were searched: Cancer Care Ontario (accessed Feb 21, 2023) Document: First Nations, Métis, Inuit and Urban Cancer Strategy 2019-2023 Indigenous Cancer Screening Resources First Nations Health Authority (accessed Feb 21, 2023) Articles: Strategy for Improving Indigenous Cancer Care Outcomes Canadian Partnership Against Cancer (accessed Feb 21, 2023)	3	3

Appendix D: PRISMA Diagram of Search Results



Appendix E: Focus Group Guide for Sharing Circle with Cancer Survivors and Their Families (Primary Study)

FOCUS GROUP GUIDE
Cancer survivors and family caregivers/supports

Preamble:

d) "Thank you for participating in our study. This group includes people who have had experience with cancer, whether it was experiencing a cancer journey themselves or being a family member of someone who experienced cancer."

d) Review study purpose

d) Review ethics & audio recording

d) Sign ethics forms

"The purpose of this session is to understand your experiences with the *healing journey binder* for people with cancer and family caregivers in Pikwakanagan community, and your opinion about what was helpful and what was challenging..."

1. For start, we will go around the room and I will ask each one of you to briefly introduce yourself and describe your experience with the *healing journey binder*.

2. In what ways did the healing journey binder help you or your family member navigate through the health care system?
    - What were some of the ways the healing journey binder improved your or your family member's cancer care journey and experience?

3. What were some of the things that made it easier for you or your family member to use the *healing journey binder*?

4. What were some of the things that made it harder for you or your family member to use the *healing journey binder*?

5. Overall, do you find that *healing journey binder* to be suitable for Pikwakanagan community?
    a. In what ways does it honour community knowledge and traditions?

6. Do you have any recommendations for modifying / adapting the *healing journey binder* further for First Nations people?
    - What other things would help you or your family member in the cancer journey? *(prompt – activities, arts, nature, spirituality, traditional practices)*

Closing comments:

b) Summarize discussion.
b) Do you have any other comments or stories you would like to share about the *healing journey binder*?

Thank you for your time

Appendix F: Focus Group Guide with Healthcare Providers (Primary Study)

FOCUS GROUP GUIDE
Health service providers

Preamble:

d) "Thank you for participating in our study."

d) Review study purpose

d) Review ethics & audio recording

d) Sign ethics forms

"The purpose of this session is to understand your experiences with implementing the *healing journey binder* for people with cancer and family caregivers in Pikwakanagan community, and your professional opinion about the benefits, challenges and facilitators along the way.

1. For start, we will go around the room and I will ask each one of you to briefly introduce yourself and describe your experience with implementing the *healing journey binder*.

2. What were the greatest challenges you encountered to implementing the *healing journey binder* for people with cancer in Pikwakanagan Health Services and Family Health Team?
    - how did you address/overcome the challenges to implementing the *healing journey binder*

3. What were the facilitators/supports to implementing the *healing journey binder* for people with cancer in Pikwakanagan
4. Health Services and Family Health Team*?*
    - how did you utilize the facilitators/supports during implementation
    - What further supports would assist with implementing the *healing journey binder*

5. In what ways did you see the healing journey binder help cancer survivors and family caregivers navigate through the health care system?
    - What were some of the ways you saw the healing journey binder improved cancer survivors and family caregivers' cancer care journey and experience

6. What were some of the things that made it easier for cancer survivors and family caregivers to use the *healing journey binder*?

7. Overall, do you find that *healing journey binder* to be suitable for Pikwakanagan community?
    a. In what ways does it honour community knowledge and traditions?

8. Do you have any recommendations for modifying / adapting the *healing journey binder* further for First Nations people?

Closing comments:
- b) Summarize discussion.
- b) Do you have any other comments or stories you would like to share about implementing the *healing journey binder*?

Thank you for your time

Appendix G: Interview Guide – One on One Interviews with Cancer Survivors and their Families

INTERVIEW GUIDE

Cancer survivors and family caregivers/supports

The purpose of the interview is to give you an opportunity to discuss some more about your experiences with the *healing journey binder* — what you liked/didn't like, what was helpful and challenging, and how the *healing journey binder* helped you or didn't help you with cancer care."

1. Can you tell me about some of the ways the *healing journey binder* improved your or your family member's cancer care journey and experience? Please explain

2. In what ways was the *healing journey binder* helpful to you or your family member to navigate through the health care system?

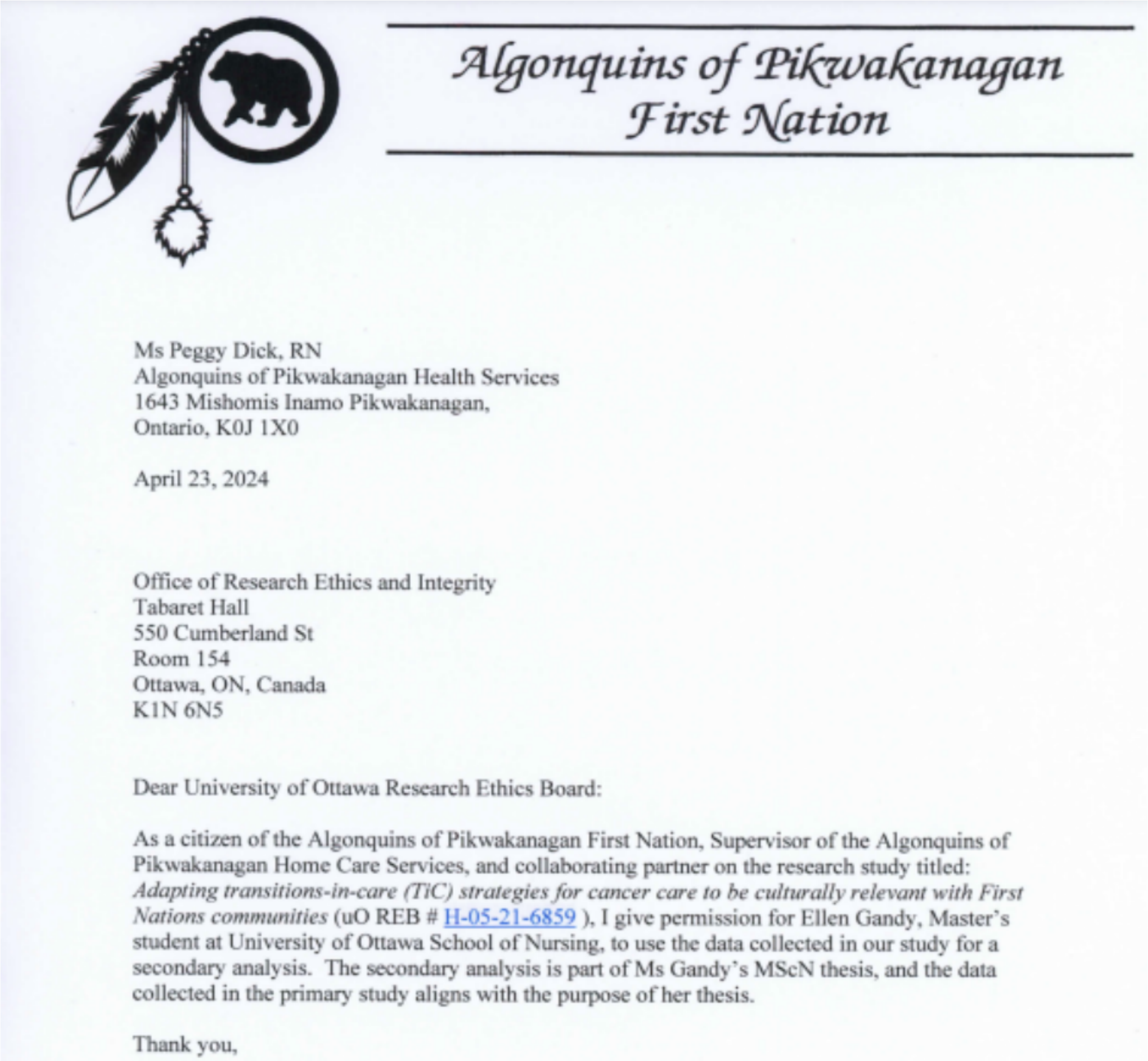
3. What made it hard or difficult to access and use the *healing journey binder*?

4. What made it easier or helped you access and use the *healing journey binder*?

5. Do you have any recommendations for making the *healing journey binder* more relevant to people in Pikwakanagan community?
    a. In what ways does it honour community knowledge and traditions?

6. What other things would help you or your family member in the cancer journey? *(prompt – activities, arts, nature, spirituality, traditional practices)*

Appendix H: Community Letter of Permission



Algonquins of Pikwakanagan
First Nation

Ms Peggy Dick, RN
Algonquins of Pikwakanagan Health Services
1643 Mishomis Inamo Pikwakanagan,
Ontario, K0J 1X0

April 23, 2024

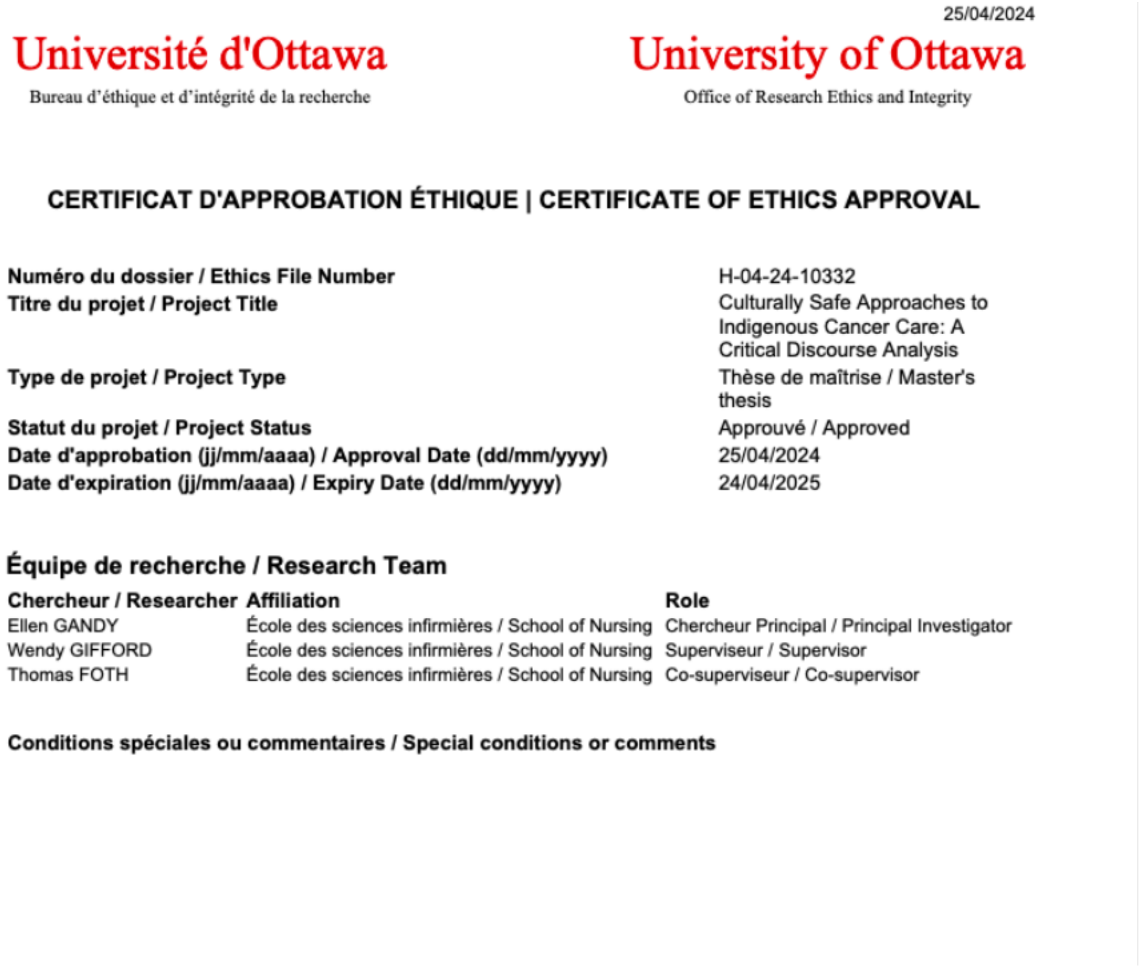
Office of Research Ethics and Integrity
Tabaret Hall
550 Cumberland St
Room 154
Ottawa, ON, Canada
K1N 6N5

Dear University of Ottawa Research Ethics Board:

As a citizen of the Algonquins of Pikwakanagan First Nation, Supervisor of the Algonquins of Pikwakanagan Home Care Services, and collaborating partner on the research study titled: *Adapting transitions-in-care (TiC) strategies for cancer care to be culturally relevant with First Nations communities* (uO REB # H-05-21-6859), I give permission for Ellen Gandy, Master's student at University of Ottawa School of Nursing, to use the data collected in our study for a secondary analysis. The secondary analysis is part of Ms Gandy's MScN thesis, and the data collected in the primary study aligns with the purpose of her thesis.

Thank you,

Appendix I: REB Ethics Form



25/04/2024

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-04-24-10332
Titre du projet / Project Title	Culturally Safe Approaches to Indigenous Cancer Care: A Critical Discourse Analysis
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	25/04/2024
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	24/04/2025

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Ellen GANDY	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Wendy GIFFORD	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Thomas FOTH	École des sciences infirmières / School of Nursing	Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments