# Access to Oncology Care among Indigenous Peoples and the Role of Nurses

by

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## Abstract

**Background:** Indigenous Peoples' health and healthcare access are of growing interest to researchers, decision-makers and practitioners alike as access to healthcare remains a complex and challenging issue. Indigenous Peoples in Canada face considerable challenges in accessing healthcare and reported differences in cancer outcomes between Indigenous Peoples and other Canadians appear, in part, to be associated with inequitable access to care. However, limited research has explored access to oncology care specifically. In particular, the perspectives of oncology nurses have yet to be explored.

**Purpose:** The aim of this thesis was to critically examine access to oncology care among Indigenous Peoples in Canada, and the perspectives of nurses on access to oncology care. A paper-based thesis addressed the following objectives: 1) to identify, summarize and analyze what is currently known about access to oncology care among Indigenous Peoples in Canada; 2) to theorize the role of nurses in improving access to care among Indigenous Peoples; 3) to explore how nurses understand the barriers, facilitators and complexities of access to oncology care among Indigenous Peoples; and 4) to explore how nurses understand their role in delivering oncology care to Indigenous Peoples and in improving access to care for this population.

**Methods:** A sequential multiple-methods qualitative research design was used. *Phase 1* involved a scoping review of the literature. Simultaneously, *phase 2* involved the development of a conceptual framework based on a critical review and analysis of literature. Informed by phases 1 and 2, and using interpretive descriptive and critical discourse analysis methodologies, *phases 3* and *4* involved an online survey of oncology nurses in Canada and follow-up in-depth interviews.

**Findings:** Results from the multiple methods study indicate a predominant focus on individual and sometimes systems level influences on access to oncology care, and a corresponding lack of attention to structural influences. Nurses' work in addressing access is similarly focused primarily at the individual patient level. Biomedical discourses significantly impact access to oncology care, and exert a strong influence on how access is framed in both research and nursing practice.

**Conclusions:** Action to address inequities in access to oncology care is urgently needed. Nurses can play an important role in this work, which should address individual, systems and structural influences on access to oncology care.

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## Dedication

To my family: Chad, Callie and Mason

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3. Appendix A, Table 1 (from the accepted version of the following article):

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# Chapter 1: Introduction

Health status and healthcare access are shaped by complex social economic and political processes. Globally, Indigenous Peoples' health and healthcare access are of growing interest to researchers, decision-makers and practitioners alike as access to healthcare remains one of the most complex and challenging issues (United Nations, 2015). In Canada, Indigenous Peoples[1] experience startling differences in health outcomes, significant barriers to healthcare access, and bear a disproportionate burden of illness and suffering (Adelson, 2005; Katz et al., 2019; Public Health Agency of Canada, 2018; Smylie & Firestone, 2016). Moreover, evidence of systematic inequities in healthcare access are well documented, despite a publicly funded healthcare system with a commitment to provide universal healthcare access (Adelson, 2005; Browne et al., 2011; McGibbon, 2016). Inequities in healthcare access exist as a result of overlapping social, economic, historical and political influences, which intersect with experiences of racism, stigma and discrimination within the healthcare system. These structurally violent conditions experienced in the everyday lives of Indigenous Peoples constitute a serious, yet remediable, concern. Within their practice, nurses witness this structural violence, and at times are complicit actors, enabling or maintaining it through unequal relations of power, social interactions and institutional processes. Underlying this thesis is an interest in the role nurses are playing in access to care, how they articulate that role, and the role they could play in addressing healthcare access.

In this thesis, I examine inequities in healthcare access among Indigenous Peoples

[1] In Canada, the term 'Indigenous Peoples' refers to three distinct groups: First Nations, Métis and Inuit peoples. Although distinct, these groups share similar colonial histories, political, social and economic conditions. I use the term Indigenous Peoples throughout this thesis to refer to these groups but acknowledge the use of First Nations peoples (FN), Métis and Inuit in this review of relevant literature. Rather than clarifying use of terms each time, I simply report based on the terminology used in articles cited.

within the context of oncology care in Canada. Indigenous Peoples experience concerning differences in cancer outcomes that appear, in part, to be associated with inequitable access to oncology care (Horrill et al., 2019a; 2019b; 2020; McGahan et al., 2017). Conditions underlying these differences in healthcare access and other structural influences are rarely considered in relation to growing cancer disparities between Indigenous Peoples and non-Indigenous Canadians (Horrill et al., 2020). As a way of shedding light on these less studied areas, this thesis focuses primarily on the perspectives of nurses regarding access to and the delivery of oncology care among Indigenous Peoples. As the largest group of healthcare providers, nurses' practice, and therefore their experiences and perspectives, emerge from the intersections of the intimate personal lives of patients, and the systems and structures that determine health status (Falk-Rafael, 2005; McGibbon & Lukeman, 2019). Moreover, nurses are often the first healthcare providers that patients encounter, and their attitudes and behaviors impact patients' willingness to seek care (Papps & Ramsden, 1996). Nurses' central role in facilitating access to care affords them unique perspectives on this topic.

In this introductory chapter, I begin by locating myself and my interest in this subject, followed by a brief background and discussion of the epistemological and theoretical foundations to contextualize the thesis. I then describe the objectives and structure of the thesis and conclude with a discussion of the significance of the thesis.

## Locating Self

Within critical and postcolonial traditions, locating oneself as a researcher allows the reader insight into whom and what is underlying the research, and is also an important component of designing and conducting the research. As Mohammed (2006) notes, "a researcher's biography, history and sociocultural position shape the questions that are

researched, how data are gathered and analyzed, social relations while in the field, and interpretive representations made after leaving the field" (p. 105). Our historical and sociopolitical positioning will grant us certain degrees of privilege and it is important that we reflect on, identify and mitigate power differentials between ourselves as researchers and those we research (Kovach, 2009). More broadly, as researchers doing critical research, we also question our positionality, and consider the ways in which we have been complicit in perpetuating inequities and injustices we seek to study (Strega, 2015).

My journey began many years ago within my clinical oncology nursing practice. Over the course of a decade, I had the privilege of walking alongside many patients and families through their cancer journey. Several years in, I began to notice a pattern: those patients who were Indigenous were being diagnosed with cancer at more advanced stages. I was curious about why this might be happening and began to have conversations with other clinicians. The general consensus was that these patterns were a result of 'lifestyle choices' and biological risk related to 'race'. The choice to inquire into cancer disparities among Indigenous Peoples in my doctoral dissertation sparked a more than four year long journey of learning – about the root causes of these disparities, the structural inequities experienced by Indigenous Peoples in Canada that have profound impacts on health, and how colonialism is embedded in the fabric of our society to the extent that it continues to impact the lives and experiences of Indigenous Peoples on an everyday basis. I learned to question the assumption that health disparities are rooted in lifestyle choices and biological risk, and that this assumption is rooted in racism.

As a white settler, I embarked on an often painful journey of examining my own biases, and how I have been complicit, whether knowingly or not, in the structural racism perpetuated by the healthcare system towards Indigenous Peoples. This learning impacted the

research questions developed for my thesis, and continued as I collected data, analyzed transcripts, wrote results, talked with nurses, and listened to mentors. My position as an oncology nurse and a white person has also impacted the ways in which I have walked through the research. As an oncology nurse, I was seen by many participants as an insider; in many interviews, nurses talked to me as if I was one of their own (and in many ways, I still feel as if I am). As a white person, I am afforded many privileges within academic and healthcare settings, and my research was seen as valuable and rigorous. However, as a white person researching inequities in access to care among Indigenous Peoples, I bring this lens to bear in my research and interpretations. That is, I will always see things from my white perspective, and will never fully understand the inequities I study from the perspective of those experiencing them. These processes of reflection and coming to a more fulsome understanding of the nature of health inequities have further inspired me in this research as I have become deeply passionate about the privileged position that nurses are in to bear witness to suffering and healing, and the potential for nurses as individuals and as a collective body to impact health equity.

## Background

Indigenous Peoples in Canada face considerable challenges in accessing healthcare, widely acknowledged as an important determinant of health (McGibbon, 2016; Whitehead & Dahlgren, 2006). Inequities in access to healthcare among Indigenous Peoples in Canada are deeply concerning, however, less is known about access to oncology care. Given the growing cancer disparities seen between Indigenous Peoples and non-Indigenous Canadians, exploring access to oncology care should be of importance.

**Cancer Trends among Indigenous Peoples in Canada: Why the Concern?**

Over the past several decades, alarming trends have been documented related to cancer incidence, patterns of diagnosis, and mortality among Indigenous Peoples in Canada. Incidence of several cancers is rising faster among First Nations peoples than other Canadians (Canadian Partnership Against Cancer, 2011, 2013; Decker et al., 2016; Mazereeuw et al., 2018a; McGahan et al., 2017); similar trends are also seen among Inuit and Métis peoples (Mazereeuw et al., 2018b; Young et al., 2016). Cancer stage at diagnosis, an important predictor of outcomes and indicator of the quality of and access to screening and early detection services (Canadian Partnership Against Cancer, 2015), is also problematic, with First Nations peoples being diagnosed with advanced cancers more often than non-Indigenous Canadians (Canadian Partnership Against Cancer, 2013; Decker et al., 2016; Horrill et al., 2019a; Sheppard et al., 2010). First Nations peoples also experience higher cancer mortality than non-Indigenous Canadians (Chiefs of Ontario & Cancer Care Ontario, 2017; Decker et al., 2016; Erickson et al., 2015; Horrill et al., 2019a; Withrow et al., 2017). Interestingly, although mortality outcomes tend to be worse for First Nations in Canada compared to non-Indigenous Canadians, cancer-related mortality between First Nations living on and off reserve is similar (Horrill et al., 2019b). Statistical data alone, however, do not allow us to explore the roots of these alarming differences, which are most often situated within what I call the ‘disparities discourse’ (Horrill et al., 2020). Causes of these disparities are frequently attributed to lifestyle ‘deficits’, and inherent race-based ‘risk’, rather than the social and structural conditions that have created and sustained them. Sinding and colleagues (2014) note a tendency within oncology research to “locate the problem of disparity with disadvantaged patients”, and a failure to consider the without broader structures in which and through which

these disparities are located (p. 3114). Poor access to and use of cancer screening services is also articulated as a potential cause of these disparities, with a corresponding assumption that increasing oncology services and education targeting lifestyle and screening would reduce these disparities. However, considering issues of access to oncology care from a different angle opens new possibilities for exploring these disparities.

**Access to Healthcare: Conceptual Definitions**

Access to healthcare is commonly assumed to be a function of the geographical and temporal location of patients in relation to healthcare services (Wilson & Rosenberg, 2004). Access may also be understood as a function of service availability, where increasing the number of healthcare facilities or healthcare providers will correspondingly improve access to care (Levesque et al., 2013; Tang et al., 2015). Yet these 'technocratic' conceptualizations fall short of providing a nuanced and fulsome understanding of healthcare access (Tang et al., 2015). Accessing healthcare is a complex process, requiring "considerable work on the part of users" and involves much more than simply presenting at a healthcare facility (Dixon-Woods et al., 2006, p. 7). A specific focus on the organization or appropriateness of services alone (Gulliford et al., 2002; Levesque et al., 2013; Wilson & Rosenberg, 2004) does not account for the complexities of negotiating access to care.

Foundational to the work contained within this thesis is a conceptualization of healthcare access as a social relationship embedded within a structural context. This conceptualization arose out of an analysis that comparatively examined healthcare access through biomedical and postcolonial lenses, which fundamentally shifted the direction of this thesis (Appendix A). Postcolonialism offers a lens through which to consider the "impact of race and power dynamics, as well as historical, political, and social influences on access"

(Horrill et al., 2018, p. 3). Thus, beyond considering the *what* and the *where* of healthcare services, a socio-relational definition of healthcare access means considering the *how* of healthcare access. The delivery of healthcare services at the point of care, and the interactions between healthcare providers and patients are a fundamental component of healthcare access (Horrill et al., 2018; Tang et al., 2015). Such socio-relational conceptualizations of healthcare access are of particular relevance to the profession of nursing, as we can and ought to play an important role in ensuring full access to healthcare. Underlying my approach to studying access to oncology care in this thesis are the frameworks of cultural safety and trauma- and violence-informed care.

### *Cultural Safety*

Drawing on postcolonial concepts, cultural safety focuses attention on the nature of healthcare relationships as an essential component in access to care, while also illuminating the impact of social and structural determinants of health on access to care (Anderson et al., 2003; Browne et al., 2009). Cultural safety, developed in the New Zealand nursing context, grew out of the recognition that the attitudes of nurses, often the first healthcare professional that patients encounter, play a significant role in a patient's willingness to seek healthcare (Papps & Ramsden, 1996; Ramsden, 2002). Underpinning a cultural safety perspective is an understanding that all nurse-patient interactions occur between two people positioned differently in relation to socioeconomic status, gender, age, ethnicity and so on (Ramsden, 2002), and that these positions are imbued with power. Indeed, Papps and Ramsden (1996) articulate that *all* healthcare relationships are power-laden *and* unequal. Power, while operating in every encounter, is not understood as a static or fixed entity that is held by specific people or professions, but rather is "negotiated in each particular encounter…and

mediated by the social signifiers of race, gender, culture, age and class" (Anderson et al., 2003, p. 209). Thus, cultural safety requires nurses to engage in reflexivity, examining their beliefs, values, and assumptions, and how these influence their nursing practice (De Souza, 2015; Papps & Ramsden, 1996). Cultural safety directs an examination not only of power imbalances within healthcare relationships, but also those that are structural – embedded within social, political and economic institutions – and those with colonial and neocolonial roots (Reimer Kirkham et al., 2002).

### *Trauma- and Violence-Informed Care*

Trauma- and violence-informed care (TVIC) recognizes the profound impacts of both trauma and violence on the lives and well-being of individuals (Elliott et al., 2005). TVIC assumes that those who are disadvantaged experience different forms of violence that have ongoing, traumatic impacts that further entrench health and social inequities (Browne et al., 2016; Varcoe et al., 2014). TVIC is particularly relevant within the Canadian context, given the historical traumas and structural inequities experienced by Indigenous Peoples and provides a backdrop for understanding that healthcare encounters risk triggering trauma responses which prevent people from accessing care (Elliott et al., 2005). TVIC is founded on providing respectful care that recognizes the effects of violence and prioritizes understanding the socioeconomic and political context of health problems (Browne et al., 2016). These frameworks, and their applicability within the context of access to healthcare are further explored in Chapter 3, however are introduced here to highlight the important role of nurses and their relationships with patients in structuring access to care.

**Examining Healthcare Access among Indigenous Peoples: A Socio-Relational Perspective**

A growing body of evidence within Canada investigating healthcare access among Indigenous Peoples points to the clinical encounters between healthcare providers and patients as highly problematic. Experiences of racism, discrimination, intimidation, harassment and fear of judgment based on race or social class in healthcare encounters are pervasive among Indigenous Peoples, and contribute to avoidance or delays in accessing healthcare (Browne, 2007; Browne et al., 2011; Cameron et al., 2014; Denison et al., 2014; Goodman et al., 2017; Hole et al., 2015; Kitching et al., 2020; Kurtz et al., 2008; Monchalin et al., 2020; Nelson & Wilson, 2018; Tang & Browne, 2008; Tang et al., 2015; Wylie et al., 2019; Wylie & McConkey, 2019). Furthermore, when healthcare services are accessed, the health concerns of patients who are Indigenous are frequently trivialized, diminished or dismissed (Browne & Fiske, 2001; Browne et al., 2011; Goodman et al., 2017; Hole et al., 2015; Tang et al., 2015). These experiences begin a 'negative feedback loop', in which patients who are Indigenous experience poor quality care, expect to receive similar care in their next encounter and subsequently delay accessing care, are admonished by healthcare providers for their delay, and further reduce their contact with healthcare providers (Browne et al., 2011; Goodman et al., 2017; Nelson & Wilson, 2018). Some patients who are Indigenous report the need to transform themselves to look and act a certain way to gain 'credibility' in order for their health concerns to be heard and understood (Browne & Fiske, 2001; Tang & Browne, 2008). Stemming from a history of colonization and substandard medical treatment, Indigenous Peoples may feel fearful, anxious, and powerless within healthcare settings, and have a deep sense of distrust towards healthcare providers (Browne et al., 2011; Cameron et al., 2014;

Goodman et al., 2017; Health Council of Canada, 2012; Nelson & Wilson, 2018; Phillips-Beck et al., 2020). This sense of distrust further contributes to delays or avoidance in seeking healthcare.

This body of research highlights the ways in which patients are encouraged or discouraged from accessing healthcare through encounters with healthcare providers, including nurses, and underscores the important role nurses can play, both positively and negatively, in healthcare access (Browne, 2005, 2007; Browne & Fiske, 2001; Hartrick Doane & Varcoe, 2015; Tang & Browne, 2008; Tang et al., 2015). Yet nurse-patient interactions are also significant as "extensions of wider post-colonial relations" (Browne & Fiske, 2001, p. 143). Nurse-patient interactions mirror daily social interactions and popular discourses about Indigenous Peoples and occur within the context of historical and ongoing colonial relations (Browne, 2005; Browne & Fiske, 2001; Hole et al., 2015; Tang & Browne, 2008; Tarlier et al., 2007). Moreover, these interactions intersect with social and structural determinants of health and health systems barriers that further limit healthcare access among Indigenous Peoples (Hole et al., 2015; Wylie et al., 2019).

**Examining Access to Cancer Care among Indigenous Peoples**

Within the context of oncology care specifically, research on the impact of patient-provider interactions or structural influences on access to care is sparse. However, from the perspectives of Indigenous patients, their families, and other healthcare providers, lack of culturally safe services and experiences of racism and discrimination have been identified as barriers to accessing oncology care (Assembly of First Nations, 2009; Black, 2009; Bottorff et al., 2001; CancerCare Manitoba, 2013; Lavoie et al., 2016; Macdonald et al., 2015; Poudrier & Thomas Mac-Lean, 2009; The Saint Elizabeth First Nations Inuit and Metis Program, 2012;

Tobias et al., 2020). These experiences are entwined with distrust of healthcare providers, personal experiences of trauma, and historical trauma within a legacy of colonialism to further constrain access to oncology care (Black, 2009; Bottorff et al., 2001; Maar et al., 2013, 2016; Russell & de Leeuw, 2012; Wakewich et al., 2016).

### Summary of Research Gap

Collectively, evidence suggests that Indigenous peoples in Canada experience considerably poorer access to healthcare in general. However, limited research has explored access to oncology care specifically, despite significant cancer-related disparities in this population. Nurses, who provide the bulk of clinical care, daily navigate the tensions between systemic and structural influences on healthcare access and the individual experiences of illness and suffering, however little is known about their work in delivering oncology care to Indigenous Peoples, or their perspectives on access to care. Moreover, from the perspectives of patients who are Indigenous, lack of culturally safe care and experiences of racism are substantial barriers to accessing care, yet nurses' perspectives on these issues within the context of oncology care are not known. The aim of this paper-based thesis is to critically examine access to oncology care among Indigenous peoples in Canada and the perspectives of oncology nurses.

## Epistemological Foundations & Theoretical Orientations

The aims of this thesis, and the ways in which those aims are addressed, are embedded in a particular epistemological stance. An epistemology, or philosophy of knowledge, establishes what constitutes knowledge, what kinds of knowledge are possible, and who can be a knower (Campbell & Bunting, 1999; Crotty, 1998). Such philosophical assumptions about the nature of knowledge are inherent in all research and in the theoretical perspectives

and methodologies chosen to guide the research (Crotty, 1998). In this section, I discuss the epistemological foundations of the thesis, the critical and postcolonial theoretical orientations of the thesis, and the application of postcolonial theoretical perspectives to the research process (Appendix B).

**Constructionism**

A constructionist epistemology holds that knowledge or meaning are constructed through engagement between the subject and object – meaning is not 'discovered' and therefore cannot exist apart from consciousness (Crotty, 1998, p. 8). Constructionists understand reality as dynamic, and constituted through experience and social interaction (Crotty, 1998; Lincoln et al., 2011; Streubert Speziale & Carpenter, 2003). Furthermore, constructionism emphasizes the role of context in constructing meaning as it "shapes the way in which we see things (even the way in which we feel things!) and gives us a quite definite view of the world" (Crotty, 1998, p. 58). Thus, knowledge is subjective, contextual, and shaped by our collective reality (Crotty, 1998; McEwen & Wills, 2014). From a critical perspective however, knowledge and meaning are socially constructed within the context of *power relationships*, with knowledge serving hegemonic purposes (Crotty, 1998). As a result of this hegemonic context, knowledge and meaning can be distorted and ideologic (Campbell & Bunting, 1999). Epistemologically, explicating the influence of power and context on the construction of knowledge can serve emancipatory aims, producing fundamental social change (Campbell & Bunting, 1999; Lincoln et al., 2011).

**Critical Theory**

Critical theory began to emerge in the 1920s through the work of the 'Frankfurt School' of scholars in response to the dominance of a scientific philosophy in which only

empirically observed, or logically deduced knowledge was valued (Campbell & Bunting, 1999). Critical theory, encompassing a range of theories and methodologies, is used to describe “the process and product of work that takes a historically situated and sociopolitical perspective” (Chinn & Kramer, 2008, p. 82). Research conducted within the critical tradition is aimed at confronting a particular injustice or inequity and is driven by emancipatory aims, premised on the assumption that knowledge production will challenge oppression and unequal power relations, and open possibilities for social and structural change (Chinn & Kramer, 2008; Kincheloe & McLaren, 2005; Lincoln et al., 2011). In other words, critical research is not conducted strictly for the purposes of increasing knowledge, but rather is explicitly political (Chinn & Kramer, 2008; Holmes et al., 2008; Lincoln et al., 2011).

Although critical theory is concerned with the ways in which race, class, gender, economics, religion, culture, discourse, and social institutions intersect and interact to construct social systems and personal experience, the concept of power is a central concern (Kincheloe & McLaren, 2005). Critical theory assumes that power is present in every social interaction, that social order is structured by relationships of domination and power, and that certain groups within society are privileged over others (Browne, 2001; Kincheloe & McLaren, 2005). From a critical perspective, power is productive, causing inequalities and oppression, and operates through language (discourses), ideologies, and institutions (Kincheloe & McLaren, 2005). Thus, research conducted in the critical vein is interested in (and critical of) how knowledge and meaning are constructed in this context. Canella and Lincoln (2009) suggest that two key questions are foundational to critical qualitative research: who or what is being helped or privilege or legitimated? And who or what is being harmed or oppressed or disqualified? For research to be considered 'critical', it must undertake an

analysis of power, including previously unseen or unnoticed sources of power (Longo & Dunphy, 2012).

**Postcolonial Theory**

Postcolonial theory falls under the umbrella of critical theory, and itself refers to a range of theories, each with specific priorities and evolving from diverse disciplines, but unified by a common concern with the legacy of colonialism and the impact of the historical past on present conditions (Mohammed, 2006; Young, 2016). Postcolonial theory does not assume that colonialism is a thing of the past, but rather, that all postcolonial societies continue to be influenced in some way by both overt and covert neocolonial processes, and works to expose, resist or counter these processes (Anderson, 2004; Ashcroft et al., 1995).

Postcolonial theory, along with other critical social theories, is rooted in analyzing power dynamics and structures that may remain invisible (Anderson et al., 2009), however is distinguished from other critical theories by its focus on 'race'[2] and colonial relations, and specifically on disrupting patterns of 'race-thinking' developed within the colonial context (Browne et al., 2005). Within health research, postcolonial theory offers a framework to draw attention to and challenge how socially constructed categories of 'race' have profound effects. Anderson (2004) argues that 'race' is not a benign construction, but shapes, in multiple ways, economic inequalities and other life circumstances that have a powerful effect on health, illness, healing and well-being" (p. 245). Although a main focus of postcolonial theory, 'race' is not necessarily privileged over other forms of oppression (Mcgibbon et al., 2014; Young, 2016). Rather, postcolonial theory draws attention to the oppressive intersectional relationships between race, poverty, gender, class and other identities (Anderson, 2002, 2004;

[2] I draw on the work of Anderson (2000, 2004) to explicitly identify race not as a biological category, but one that is socially constructed, and is neither neutral nor benign.

Young, 2016). The importance of taking an intersectional approach is emphasized by McGibbon and colleagues (2014) who argue that "oppressions in society do not operate independently. Rather they intersect in intricate patterns that compound oppression…[and] interact to form an oppressive whole that cannot be disentangled into any single phenomenon" (p. 182).

Within nursing and health research, the role of history and colonial processes in creating and sustaining health inequities is often ignored (Mohammed, 2006). Postcolonial theory is useful in facilitating contextualized analyses of health inequities that account for their social, historical, political and economic roots, and revealing they ways in which health inequities are a product of colonialism and 'race-thinking' (Browne et al., 2005; Kirkham & Anderson, 2002; Mohammed, 2006). In this thesis, postcolonial theory is used to explicitly identify and analyze the structural roots of inequitable healthcare access, and the ways in which multiple forms of inequity are intersecting. Postcolonial theory is also an effective tool to understand the operations of power and privilege in nursing contexts, the role of nursing as a profession in perpetuating and reproducing health and social inequities, and the discourses shaping nursing practice itself (Anderson, 2002; Holmes et al., 2008; McGibbon et al., 2014; Mohammed, 2006).

In summary, postcolonial perspectives take a socially and historically situated approach to critically analyzing unequal relations of power and unjust social processes that result in colonized peoples bearing the disproportionate burden of illness and suffering (McGibbon et al., 2014). Postcolonial perspectives are used in this thesis to guide a critical exploration of access to oncology care, which takes into account the intersecting impacts of historical and colonial relations, 'race', racism, poverty, class and other social locations on

healthcare access. Postcolonial perspectives guided the study design to specifically inquire into nurses and their encounters with patients within the context of power relations. Postcolonialism is used here to analyze power relations at the micro level (i.e., nurse-patient encounters), meso level (i.e., power relations within healthcare systems) and at the macro level (i.e., power and discourse at the societal level). I focus some of my analyses on the language used by nurses and other healthcare providers to expose how language becomes a mechanism of power and tool of oppression. These perspectives were also chosen with the specific aim of moving away from research that locates 'problems' within Indigenous Peoples and opens space to consider issues of inequitable access to care in new ways.

## Objectives & Structure of the Thesis

The aim of this paper-based thesis is to critically examine access to oncology care among Indigenous Peoples in Canada, and the perspectives of nurses on access to oncology care. Given the limited evidence base regarding access to oncology care among this population and current conceptualizations of access, a paper-based thesis was chosen to facilitate knowledge development in multiple areas. The specific objectives of the paper-based thesis are:

1. To identify, summarize and analyze what is currently known about access to oncology care among Indigenous Peoples in Canada;
2. To theorize the role of nurses in improving access to care among Indigenous Peoples;
3. To explore how nurses understand the barriers, facilitators and complexities of access to oncology care among Indigenous Peoples;
4. To explore how nurses understand their role in delivering oncology care to Indigenous Peoples and in improving access to care for this population.

To address the objectives of the thesis, a sequential multiple-methods qualitative research design was selected (Cresswell, 2011). *Phase 1* involved a scoping review of the literature. Simultaneously, *phase 2* involved the development of a conceptual framework. Informed by phases 1 and 2, *phase 3* involved an online survey of oncology nurses in Canada (n=78), and *phase 4* concluded the study with individual in-depth interviews of oncology nurses (n=15). The structure of the paper-based thesis includes this introductory chapter, four published/publishable papers (Chapters 2, 3, 4, 5) guided by the objectives listed above, followed by a concluding chapter, which discusses the findings of the thesis as a whole. To allow readers insight into the full paper-based thesis I provide a brief overview of each chapter, however a more detailed discussion of specific methodologies and methods used is presented in each chapter. Ethical review and approval were obtained from the University of Manitoba, Education & Nursing Research Ethics Board and CancerCare Manitoba (Appendix C); oaths of confidentiality were signed by the researcher, supervisors, research coordinator and transcriptionists prior to the start of data collection (Appendix D). Of note, references, tables and figures are self-contained within each chapter, and appendices, where referenced, are included at the end of the thesis.

**Chapter 2: Access to Cancer Care among Indigenous Peoples in Canada: A Scoping Review**

To address the first objective, a scoping review of the literature was conducted (Horrill et al., 2019c). The research questions specific to this review were: a) what are the barriers to accessing oncology care for Indigenous Peoples in Canada; and b) Where along the continuum of oncology care do these barriers lie? The scoping study design was guided by the seminal work of Arksey and O'Malley (2005), and enhancements as developed by Levac et al. (2014;

2010). In this review, I critically review, synthesize and analyze what is currently known about access to oncology care among Indigenous Peoples in Canada. Through the analysis conducted, a framework emerged to locate the types of barriers to accessing oncology care identified within the literature as individual, systems and structural barriers; the predominant focus on individual and systems level barriers was noteworthy. In addition to a narrative discussion of findings in these three key areas, I also plotted the barriers identified within each included study on a continuum of care (screening, diagnosis, treatment, survivorship, palliative care), which highlighted the disproportionate focus of current research on access to cancer screening services. The scoping study resulted in a broad understanding of the current state of the science, and highlighted key gaps in current knowledge, which included a paucity of nursing perspectives on this important topic.

**Chapter 3: Nurses as Agents of Disruption: Operationalizing a Framework to Redress Inequities in Healthcare Access among Indigenous Peoples**

The main objective of this paper was to theorize the role of nurses in improving access to care among Indigenous Peoples (Horrill et al., 2020). The specific questions guiding this work were: a) how can the concepts of cultural safety and trauma- and violence-informed care inform our understanding of inequities in access to healthcare? and b) how could these perspectives be applied by nurses to improve healthcare access? Through this lens, I discuss inequitable access to healthcare among Indigenous Peoples with a particular focus on the ways in which nurses can perpetuate or redress these inequities through their interactions with patients. I propose a framework highlighting three domains for nursing action: practicing reflexivity, prioritizing relationships and considering the context. This framework provides guidance and actionable strategies for nurses to integrate cultural safety and trauma- and

violence-informed care into their work with Indigenous Peoples to specifically address healthcare access.

**Chapter 4: A Critical Exploration of Nurses' Perspectives on Access to Oncology Care among Indigenous Peoples: Results of a National Survey**

The objectives of this paper were to examine: a) oncology nurses' perspectives of the barriers to accessing oncology care among Indigenous Peoples, and b) how oncology nurses understand their role in improving access. These objectives were addressed through a national online qualitative survey, guided by an interpretive descriptive methodology (Thorne, 2016). Data analysis was also informed by critical discourse analysis (Cheek, 2000). Oncology nurse participants identified a wide range of barriers to accessing oncology care, however, their narratives centered on barriers and challenges to accessing care at the individual and systems level, with limited attention to the structural influences on access to care. These narratives extended into their understandings of their role in mediating access to oncology care. Although most nurses saw themselves as active participants working alongside or on behalf of patients to bridge gaps in care, their actions were also primary directed at the individual patient level through care coordination, system navigation and education.

**Chapter 5: Access Denied: Nurses' Perspectives on Access to Oncology Care among Indigenous Peoples in Canada**

The objectives of the fourth and final publishable paper in this thesis were to examine: a) how nurses understand access to and the delivery of oncology care among Indigenous Peoples; b) how nurses define their work within the delivery of oncology care to Indigenous Peoples; and c) the underlying discourses that shape both nursing practice and access to healthcare. These objectives were addressed through in-depth semi-structured interviews with

oncology nurses. Interpretive descriptive (Thorne, 2016) and critical discourse analysis (Cheek, 2000) methodologies guided the study design and analysis of data. The findings of the analysis paint a picture not only of the complexity of accessing care among Indigenous Peoples, who experience barriers that are layered and intersecting, but also of how oncology nurses are working to address these barriers yet are limited by organizational and systemic contexts. These findings provide insight into the discourses influencing nursing practice and shaping healthcare access.

**Chapter 6: Discussion & Conclusion**

The final chapter provides a summary and discussion of the synthesized thesis findings, notable differences in findings, and contributions to advancing knowledge in the area of healthcare access and Indigenous Peoples. The chapter concludes with a discussion of limitations of the thesis and knowledge translation strategies.

## Significance of the Paper-Based Thesis

Access to healthcare and oncology care tend to be understood in a limited way. This thesis advances our understanding of access to oncology care beyond considerations of the availability and location of services by centering the social and structural processes underlying healthcare access. In particular, this work advances knowledge on access to oncology care among Indigenous Peoples from the unique perspectives of oncology nurses, whose voices are largely absent in the current literature. Nurses provided important insights into the challenges surrounding access to oncology care and drew attention to the actual and potential work of oncology nurses in addressing these inequities. The role of nurses is not often considered in relation to healthcare access, however this thesis opens space to not only see the valuable work being done by nurses, but to consider where and how we, as a profession, could better

confront inequities in access to oncology care for Indigenous Peoples by addressing healthcare access at all levels.

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## Chapter 2: Preamble

Chapter 2 presents the first step taken to critically examine access to oncology care. A scoping review of published and grey literature was conducted to map the current state of the literature on access to oncology care among Indigenous Peoples in Canada, with a specific focus on how barriers to accessing oncology care were being investigated. Data on the accessibility of oncology services for Indigenous Peoples in Canada is piecemeal, and prior to this review, few resources existed that collated research to provide a national picture. The scoping review findings are reported as a narrative summary which paints a broad picture of what is currently known in this area and identifies key gaps in research. The analysis suggests that to date, research has primarily focused on or reported individual and systems level factors impacting access to oncology care, with significantly less attention to structural factors, including the impacts of colonialism. In addition, few studies included perspectives of nurses. This key gap (the relative absence of nursing perspectives) informed the design of multiple-methods study, in which oncology nurses' perspectives on access to oncology care were sought.

### Clarifications Regarding Search Parameters

The decision to limit the search to articles published between 1996 and 2019 was made in response to a preliminary literature search conducted by Janice Linton, and a recognition that the landscape of Indigenous health research changed significantly in 1996, with the publication of the Royal Commission on Aboriginal Peoples. The decision to limit the review to research situated within Canada was made in recognition that health systems and health services delivery varies significantly between countries and as a way to ensure that the student project was feasible.

**Author Contributions**

This paper was published in August 2019, in *Social Science & Medicine*. As the student, I led the team in all stages of the review. I conceptualized the research questions, developed the search strategy and conducted the literature search in collaboration with Janice Linton (Indigenous Health Librarian, University of Manitoba), screened studies for inclusion, developed the data extraction form, extracted data from included studies, synthesized and analyzed the included studies, and wrote and revised the manuscript. Dr. Schultz contributed to the development of the research questions, abstract and full text screening, development of the data extraction form, and analysis of extracted data. Drs. Schultz, Martin and Lavoie provided critical feedback throughout the development of the manuscript.

**Appendices associated with this chapter:**

Appendix E – Full search strategy (not included in the published paper)

Appendix F – Data extraction form (not included in the published paper)

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## Abstract

The inequities in access to healthcare documented and experienced by Indigenous peoples in Canada are startling given Canada's publicly funded and 'equally accessible' healthcare system, however little is known about access to *cancer* care, and *barriers* to accessing cancer care in particular. We conducted a scoping review to identify what is known about barriers to accessing cancer care among Indigenous peoples in Canada (including barriers to accessing cancer services, and barriers to receiving optimal care once those services were accessed), and to identify where along the cancer continuum (screening, diagnosis, treatment, etc.) these barriers are located. We searched SCOPUS, EBSCOhost, Google Scholar, Ovid MEDLINE and Ovid EMBASE for studies published between 1996 and 2019 that examined access to cancer care for Indigenous peoples in Canada; 36 studies were included in our analysis. Our review indicates that Indigenous peoples face barriers to accessing care at the individual level (factors at the level of the individual patient or healthcare provider (HCP) that impede access to cancer care), at the systems level (factors stemming from the healthcare system and its structure), and at the structural level (factors that are embedded within and systematically produced political, historical, social or economic structures). While barriers to accessing cancer care were found throughout the trajectory, there remains a disproportionate focus on access to cancer *screening*. Moreover, some barriers to accessing cancer care, such as racism, discrimination and lack of culturally safe care, although rooted in structural factors, were inconsistently framed as individual and/or systems factors. This suggests that while there is growing awareness of the impact that racism and discrimination have on access to cancer care at the individual level for example, there remains a lack of understanding of how these issues are linked with systemic and structural issues.

## Access to Cancer Care among Indigenous Peoples in Canada: A Scoping Review

Cancer among Indigenous peoples in Canada has emerged as a significant health concern: rising incidence, later diagnosis, and poorer survival rates suggest growing inequities and disparities between Indigenous peoples and non-Indigenous people in Canada (Decker et al., 2016; Mazereeuw et al., 2017). Many factors influence health disparities, including challenges in accessing healthcare, known to be a determinant of health (McGibbon, 2016). The inequities in access to healthcare experienced by Indigenous peoples in Canada are startling given Canada's reputation for having a publicly funded healthcare system equally accessible to all citizens. However, little is known about access to *cancer* care specifically, and the *barriers* to accessing cancer care in particular. In this review, we aim to develop a better understanding of both the nature and scope of the barriers to accessing cancer care among Indigenous peoples in Canada.

## Background

We begin with providing a brief overview of historical and current contextual landscape specific to Indigenous peoples within Canada. We then address how healthcare services are funded and delivered for Indigenous peoples in Canada (which differ between First Nations, Métis and Inuit, as well as between Indigenous peoples and non-Indigenous Canadians), and how these contextual factors influence access to healthcare services.

### Indigenous Peoples in Canada – Historical Perspectives

Within Canada, Indigenous peoples include three distinct groups – First Nations, Métis and Inuit. These groups have lived and experienced a colonial system of control and oppression for more than 400 years (Battiste, 2000; Reading, 2015; Smith, 2012). Although colonial structures and processes have varied by time period, geography and Indigenous group

(Smylie & Firestone, 2016), they have produced “social and material inequities that result in health disparities that persist over several generations" (Reading, 2015, p. 3). Both the *Indian Act* and the residential school system are key examples of tools of colonial oppression against Indigenous peoples in Canada.

The *Indian Act* of 1876 is a paternalistic, ‘race’-based policy, which gives the federal government the authority to specify who may ‘qualify’ to register as an Indian under the law; at present, this includes Inuit and some First Nations (FN). FN eligible for registration under the *Act* are referred to as ‘registered’ or ‘status *Indians*’; those that are not eligible for registration are referred to as ‘non-status’ First Nations. Historically, the *Act* also imposed a ‘reserve’ system, which forced the relocation of status FN to designated specific tracts of land, and restricted their movement on and off of these reserves (Reading, 2015). Many reserves were and continue to be located in extremely remote areas of Canada, and some remain inaccessible by land. In addition, many reserves were insufficient to produce food, and lacked access to potable water and sufficient housing (Reading, 2015). Despite these challenges, some FN have remained in these communities, where they were born and raised, and continue to engage in traditional food harvesting, ceremony, cultural and spiritual practices (de Leeuw et al., 2018; Waldram et al., 2006).

The residential school system functioned in Canada between 1883 and 1996, with more than 150,000 Indigenous children passing through the system during this time (Truth and Reconciliation Commission of Canada [TRC], 2015). This system saw children as young as two forcibly removed from their homes and placed in a school, with the intent of 'civilizing' them (Freeman, 2018; TRC, 2015). Once at a residential school, children were stripped of their belongings, separated from their siblings, and forbidden to speak their own language

(TRC, 2015). Children lived under the supervision of nuns and priests while receiving substandard education, subsisting on a meager diet, living in overcrowded and unsanitary dorms, and subjected to physical labor. Toward the goal of 'civilizing' Indigenous populations, "physical, emotional, and sexual abuse; deprivation, humiliation, and social isolation were often employed to break the Indigenous pupil" (Tomascik et al., 2018, p. 58), and many children died while in attendance at these schools (TRC, 2015). These horrific conditions have resulted in widespread historical and intergenerational trauma among Indigenous peoples in Canada. Historical trauma can be understood as the result of "multiple emotional and psychological wounding experiences over a person's life" (Freeman, 2018, p. 45). Furthermore, when traumas are focused on one particular group, the suffering begins to extend to family members and entire communities, beginning the process of intergenerational trauma (Freeman, 2018; Tomascik et al., 2018). The traumatic effects of the residential school system and colonial oppression have had profound and long lasting impacts on the health and wellbeing of Indigenous peoples in Canada (Freeman, 2018; Smylie & Firestone, 2016).

**Indigenous Peoples in Canada – Current Context**

Despite these traumatic historical realities, Indigenous peoples in Canada continue to demonstrate resilience, strive towards holistic wellness, and demonstrate the importance of engaging with traditional practices as part of health and wellbeing (First Nations Information Governance Centre, 2018; National Collaborating Centre for Aboriginal Health [NCCAH], 2013). Many Indigenous communities have and continue to take steps towards greater self-determination (Canadian Council on Social Determinants of Health, 2013). Since 2006, the Indigenous population within Canada has grown by 42.5% - four times faster than the non-Indigenous population (Statistics Canada, 2017). At present, approximately 4.9% of the

Canadian population identify as Indigenous, with 2.8% claiming First Nations (FN) identity, 1.7% Métis identity, and 0.2% Inuit identity (Statistics Canada, 2019). Indigenous peoples are a diverse population: in addition to Inuit and Métis peoples, FN people represent over 50 nations in 630 communities (Statistics Canada, 2019). There are more than 50 Indigenous languages spoken within Canada, with Cree, Inuktitut, and Ojibway being the most commonly spoken (Statistics Canada, 2019). Approximately 16% of FN, 57% of Inuit and 1% of Métis peoples claim an Indigenous language as their first language (Statistics Canada, 2019). Approximately 39% of Indigenous peoples live in rural areas, 30% in urban areas, and the remainder in small or medium sized communities (Statistics Canada, 2019). Among status FN people, 44% live on reserves, while approximately 73% of Inuit people live in their traditional territories of Nunangat, located in the far north of Canada (Statistics Canada, 2019).

Indigenous peoples in Canada continue to experience significant social, economic, cultural and political inequities (Adelson, 2005; Smylie & Firestone, 2016). Unemployment rates are higher among Indigenous peoples compared to non-Indigenous Canadians, and annual incomes are significantly less (Smylie & Firestone, 2016). Fewer Indigenous peoples have completed secondary or post-secondary education compared to non-Indigenous Canadians (Smylie & Firestone, 2016). Inadequate housing, lack of safe drinking water and food insecurity are also more common among Indigenous peoples in Canada (Smylie & Firestone, 2016). These inequities, many of which are a direct result of colonial policies such as the *Indian Act* and residential school system have had profound and intergenerational impacts on Indigenous health and wellbeing (Adelson, 2005; Smylie & Firestone, 2016). However, recent evidence indicates improvements in educational attainment, reductions in some chronic diseases on FN reserves, improvements in mental health, and the increasing

development of community-based and culturally relevant wellness programs (First Nations Information Governance Centre, 2018), which point toward the strength and resiliency of Indigenous peoples. Moreover, increasing attention is being paid to determinants of health that extend beyond the social, and include spirituality, relationships to land, geography, culture, language, Indigenous knowledge, and colonialism (both historical and contemporary) (de Leeuw et al., 2018).

**The Canadian Healthcare System & Indigenous Peoples**

In Canada, the *British North America Act* of 1867 delegates responsibility for the provision of healthcare services to the provincial governments. The *Act* also specifies that 'Indians' (those registered with the federal government of Canada, often referred to as 'status First Nation' or 'registered Indians' in addition to Inuit) are the purview of the federal government, however, the *Act* is silent in regards to provision of healthcare services to 'Indians' (Lavoie, 2013). The federal government provides and/or funds some healthcare services to status FN living on-reserve (Lavoie, 2013). For Inuit living in their traditional territories, healthcare services are provided by the territorial governments, or in Quebec and Newfoundland through federal-provincial arrangements. The federal government maintains that healthcare services are provided to FN and Inuit on compassionate grounds rather than out of a legal responsibility (Lavoie, 2018; Waldram et al., 2006). Thus, a jurisdictional divide is created for many First Nations, who access some care provided by the federal government (primarily public health and health promotion), and some by the provincial government (i.e., acute care, diagnostics) (Lavoie et al., 2010). Inuit typically access specialized care far from their traditional territories within Nunangat, in provincial cities where few services are responsive to Inuit culture. Métis people remain largely invisible in legislation.

**Access to Healthcare**

Indigenous peoples in Canada are reported to experience inequitable healthcare access, an important determinant of health (McGibbon, 2016). Rural and remote Indigenous communities are particularly disadvantaged (NCCAH, 2011). Low population density, poor transportation infrastructure, extreme weather conditions that often stop transportation to and from communities for a few days to weeks, and difficulty in retaining healthcare professionals mean that healthcare services in these communities can be limited, with long wait times (NCCAH, 2011). Financial barriers combined with a complex and fragmented healthcare system compound barriers to accessing healthcare (NCCAH, 2011; Public Health Agency of Canada, 2008). These geographic and financial barriers to accessing care reflect a common understanding of accessibility of healthcare services as dependent on the proximity of the patient to those services (Horrill et al., 2018). This understanding of access may be shifting, as healthcare providers are increasingly challenged to consider other factors that influence healthcare access.

Emerging evidence suggests that healthcare services and access to those services are influenced by both clinical *and* social factors. Therefore, access to healthcare is determined not only through the *location* and *availability* of services and providers, but also through the *delivery* of services at the point of care (Tang et al., 2015). Research suggests that these social spaces significantly shape access to primary care: experiences of racism, intimidation, harassment, dismissal and fear of stigmatization based on race or social class can contribute to avoiding, delaying or negating access to healthcare for Indigenous peoples in Canada (Browne et al., 2011; Cameron et al., 2014; Tang & Browne, 2008; Tang et al., 2015).

Access to cancer care in particular is also problematic: poor access to services including cancer screening (Assembly of First Nations [AFN], 2009), diagnostic testing (Canadian Partnership Against Cancer [CPAC], 2011), survivorship care and palliative care (Canadian Partnership Against Cancer [CPAC], 2013) have been documented. Poor access to cancer care may be contributing to the cancer-related disparities seen among Indigenous peoples in Canada, including higher incidence of some screen detectable cancers, such as cervical and colorectal cancer (Chiefs of Ontario & Cancer Care Ontario, 2017; Decker et al., 2015; McGahan et al., 2017; Young et al., 2000), diagnosis at later stages of cancer (Alvi, 1999; Decker et al., 2016; Sheppard et al., 2010), and poorer survival (Alvi, 1999; Chiefs of Ontario & Cancer Care Ontario, 2017; Erickson et al., 2015; McGahan et al., 2017; Nishri et al., 2015; Withrow et al., 2017). However, in Canada, data on access to cancer care for Indigenous peoples is piecemeal, and no national picture currently exists. A scoping study was designed to address this gap.

## Study Design & Methods

Scoping studies are intended to address broad research questions, map the evidence available on a particular research topic, or identify gaps in research (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac et al., 2010). The purpose of this scoping study was to construct a map of the current evidence available on accessing cancer care among Indigenous peoples in Canada, and to identify key gaps in the published and grey literatures. The design of this scoping study was based on the seminal work of Arksey and O'Malley (2005) and enhancements to this work by Levac et al (2010). As such, this protocol is organized into five stages, expanded upon below.

**Stage 1: Identification of the research question**

The first stage involved defining the research question, which clearly articulates the concept under study, and the population and outcomes of interest (Arksey & O'Malley, 2005; Levac et al., 2010). We designed this scoping study to answer the following research questions: 1) What are the barriers to accessing cancer care for Indigenous peoples in Canada? 2) Where along the cancer care continuum do these barriers lie? Healthcare systems vary significantly between countries, thus for clarity, we have limited our review to studies conducted within the Canadian context. Our target population was Indigenous peoples, which in Canada includes First Nations, Métis and Inuit peoples.

Key concepts within our research question include 'access' and 'cancer care'. Although the precise definition is contested (Anderson et al., 2008), access to healthcare services is typically understood within Canada to refer to the ability to obtain medically necessary healthcare services (those provided by hospitals or physicians) without financial costs or excessively long waiting periods (Thompson, 2016). We extend this definition of access to include physical accessibility (referring to the geographical proximity to healthcare services, availability of healthcare services and/or access to health care providers) *and* social accessibility (referring to the delivery of services at the point of care, and the nature of the relationships between healthcare provider and patient) (Horrill et al., 2018). As such, access may be understood as existing on a continuum. Cancer care can also be understood as a continuum, which includes primary care (screening, diagnosis, or follow-up care), tertiary care hospitals (surgery, inpatient admission), provincial cancer centers (diagnosis, treatment, follow-up, palliative care) and community settings (follow-up, supportive and palliative care). These concepts are defined in Table 1.

**Table 1**

*Definition of key concepts*

| Concept | Definition |
|---|---|
| **Access** | The freedom or ability to obtain or use the full continuum of healthcare services; mediated by the availability, cost, quality, timeliness and proximity of services, as well as the degree to which services are perceived as socially safe and offered as options to the patient. |
| **Cancer care** | Any health service related to the screening, diagnosis, treatment or follow-up (survivorship care or palliative care) of cancer, regardless of setting (community, hospital, etc.). |

**Stage 2: Identification of relevant studies**

Identifying relevant results involves balancing the breadth and depth of the scoping review with feasibility (Arksey & O'Malley, 2005). We searched the following electronic databases: SCOPUS, EBSCOhost (including Academic Search Complete, Canadian Reference Centre, CINAHL, and Bibliography of Native North Americans), Ovid MEDLINE and Ovid EMBASE. A comprehensive search strategy was used that included key words and subject headings applicable to each database. An academic health sciences librarian with 20 years' experience working in Indigenous health (JL) collaborated with the first author (TH) to develop the search strategy and execute the searches. A two-pronged approach to comprehensively search the bibliographic databases was used. First, keyword searching was used to search Scopus so that we could retrieve articles relevant to the Indigenous populations in Canada from the Medline and Embase databases and other resources found in Scopus. This allowed for matches to author keywords, and keywords in titles, abstracts, and references. Similar keyword searching was carried out in Ebscohost. Secondly, searching was also carried out in Medline and Embase using OVID. For these searches the librarian used a more structured approach relying on subject headings and keywords. Filters designed by health

sciences librarians at the University of Alberta were modified slightly and used for the OVID searches (sample search strategies included in Appendix A) (Campbell et al., 2013b, 2013a). Publications included in this review were limited to English language articles and grey literature published between 1996 and April 2019. Searches were also carried out using Google Scholar, to identify additional scholarly publications, which might have been overlooked in the bibliographic databases. We searched for grey literature using Google Advanced. We followed up our search of electronic databases with snowball sampling (Damschroder et al., 2009), including backward reference searching and forward reference searching of articles identified for inclusion. Finally, we scanned the tables of contents of key journals not sufficiently or wholly indexed in Medline or EMBASE (International Journal of Indigenous Health and the Journal of Indigenous Wellbeing, formerly Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health). We also consulted an expert and knowledge user (AW), a nurse educator and navigator that works closely with Indigenous patients to assist them in accessing cancer care. AW provided additional grey literature not identified in our literature search.

**Stage 3: Study selection**

The selection of studies for inclusion was an iterative process, as recommended by Levac et al (2010), in which we searched the literature, refined the search strategy and inclusion criteria, and reviewed articles for inclusion. Our inclusion and exclusion criteria were developed iteratively as we screened titles and abstracts (Table 2).

**Table 2**:

*Inclusion and exclusion criteria*

| Criteria | Inclusion | Exclusion |
|---|---|---|
| **Language** | English | Other |
| **Country** | Canada | Other |
| **Date** | 1996-2018 | Other |
| **Population** | Indigenous (First Nation, Métis, Inuit) | Other |
| **Focus of study** | Access to/delivery of cancer services | Epidemiological studies, cancer prevention, or other |

We used a three-step process for study selection, using the inclusion/exclusion criteria identified above:

1) A single reviewer (TH) screened the titles of all articles identified through electronic database searches and snowball sampling.
2) Two reviewers (TH and ASH) independently screened abstracts of articles included in Step 1 for eligibility, noting the primary reason for exclusion where applicable. Reviewers met upon completion to compare results and resolve discrepancies.
3) Two reviewers (TH and ASH) independently read the full texts of articles included in Step 2 for eligibility to determine the final set of included articles.

We used Covidence (https://www.covidence.org/), the standard platform for Cochrane Reviews, to manage study selection. Study selection is reported as per PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) in Figure 1.

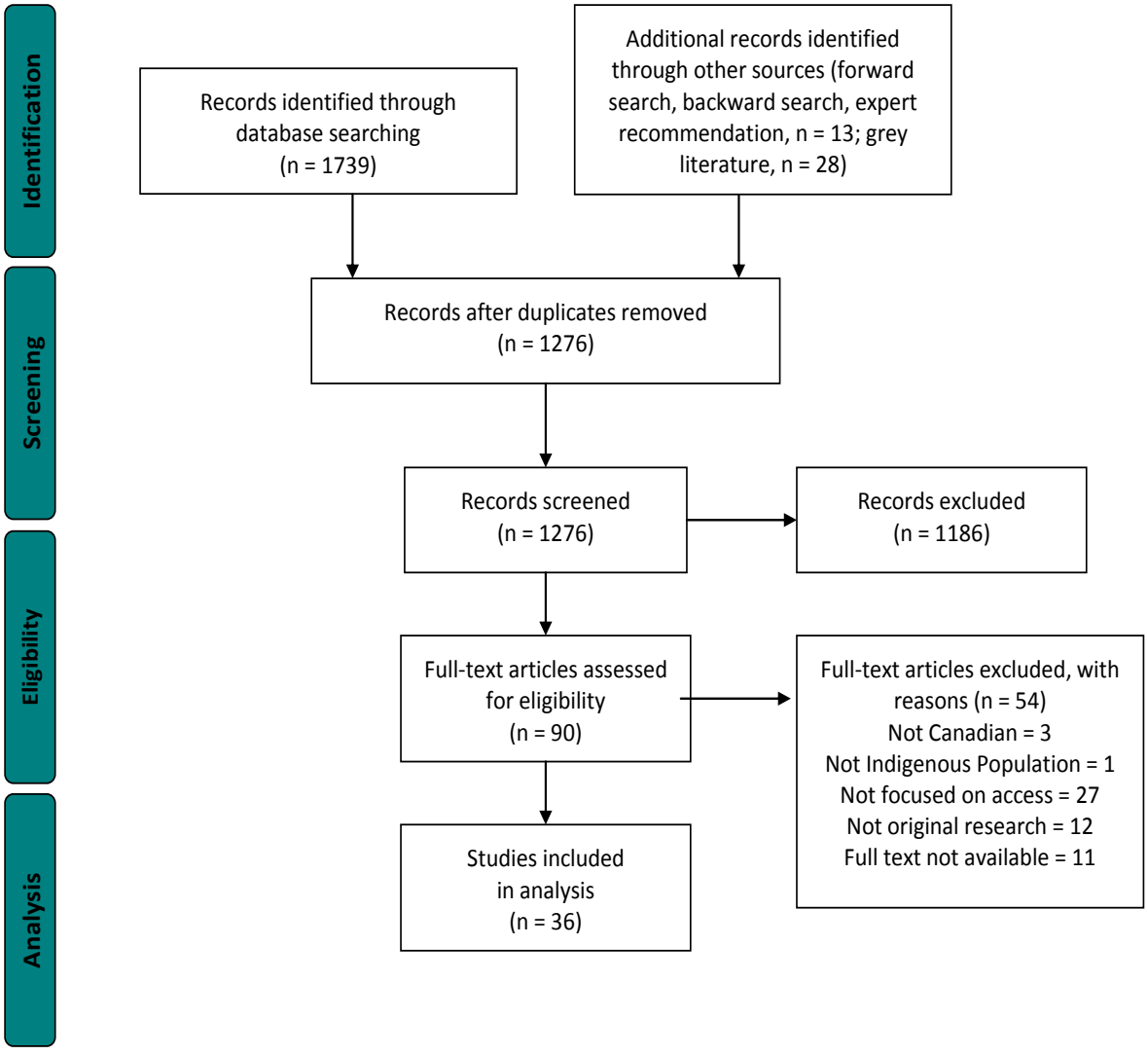
**Stage 4: Charting the data**

One reviewer (TH) extracted data from the full texts of articles included in the review using a standardized extraction form, using descriptive analytical techniques (Arksey & O'Malley, 2005; Levac et al., 2010). The data extraction form was iteratively developed (TH, JGL, ASH) throughout data charting to ensure the data extracted reflected the aim of the

scoping review. For each included article, we charted: author(s), publication details, location of study by province, population of interest, sex of interest, sample/size, study aim, methodology, level of research engagement with Indigenous peoples, location of barriers on the cancer care continuum, and the barriers to accessing cancer care identified in that study (selected data are reported in Table 3, which can be found immediately following the reference list).

**Figure 1**

*Study Selection*



### Stage 5: Collating, summarizing and reporting the results

The final stage involved analysis of the data charted, reporting of results, and determining the implications of findings (Arksey & O'Malley, 2005; Levac et al., 2010), which was a collaborative process among all authors. The results are reported here as a narrative summary of study findings. We begin by describing the type of studies included, followed by a thematic analysis of barriers identified in the included studies to accessing cancer care among Indigenous peoples, and conclude with a discussion of the implications of our analysis.

## Results

A total of 36 studies were included in our scoping review (Table 3). Of the studies included, two thirds were peer-reviewed journal articles (n=23), with the remaining one third consisting of grey literature (reports and theses; n=13). With the exception of 2009 in which there were five studies published, few studies were published in each of the years between 1996 and 2011 (between 0 and 2 each year). More sustained research attention to cancer care access was seen between 2012 and 2017, ranging between two and nine studies published in each of these years.

The majority of included studies focused solely on First Nations populations (n=29), while two reported on both First Nation and Métis populations, three studies focused on Inuit populations, and two did not specify (used undefined terminology of "Aboriginal"). Almost half of the studies focused exclusively on women (n=17). Studies included for analysis reported on a range of participants, including health professionals and/or paraprofessionals (n=15), Indigenous individuals (including community members and non-healthcare providers;

n=13), Indigenous cancer patients or survivors (n=14), caregivers and/or family members (n=8), and "key informants" (not otherwise specified; n=2).

Of the studies included, most reported on qualitative studies (n=30); the remainder of studies included mixed methods (2), survey (1), randomized controlled trial (1), intervention study (1), and retrospective study (1). As we extracted data related to the methodology used in the studies included, we became interested in if and how each of these studies included or engaged Indigenous peoples. Research involving Indigenous peoples must be premised on establishing respectful relationships that demonstrate meaningful engagement and collaboration and is necessary ensure the harms of the past are not perpetuated anew (Government of Canada, 2014). We adapted a scale of public participation (IAP2 International Federation for Public Participation, 2018) to evaluate the level of engagement with Indigenous peoples in each of the studies included (Table 4). We found a wide range of engagement, varying from no reported involvement, to Indigenous-led studies, with more than one third of studies demonstrating collaborative research engagement (n=14).

**Table 4**

*Spectrum of Indigenous Involvement in Research*

| **Level of Engagement** | **Goal of Indigenous Engagement in Research** |
|---|---|
| **None/Not Specified (n=10)** | No reported engagement, or insufficient detail to determine the level of engagement. |
| **Inform (n=2)** | To provide Indigenous peoples with information about the research project, and assist them in understanding the research problem and/or findings. Examples: meetings with Indigenous community members or Elders to inform about the research project. No control in the research process. |
| **Consult (n=2)** | To obtain Indigenous ***feedback*** on the research process, data analysis, research findings, and/or decisions to implement research findings. Examples: meetings with Indigenous community members or Elders to get feedback on the research project. No control in the research process. |

| | |
|---|---|
| **Involve (n=5)** | To *work directly with* Indigenous peoples throughout the research process to ensure that Indigenous concerns and aspirations are understood and considered. Examples: Indigenous advisory group; community members as data collectors. Little or no control in the research process. |
| **Collaborate (n=14)** | To ***partner with*** Indigenous peoples in each aspect of the research process, including the research design, execution, data analysis, interpretation and dissemination of findings. Examples: part of the research team; role in shaping the research study. Some control in the research process. |
| **Lead (n=3)** | To have Indigenous peoples ***lead*** the research process, including the research design, execution, data analysis, interpretation and dissemination of findings. Examples: leading methodological decisions, first authorship. Full control in the research process. |

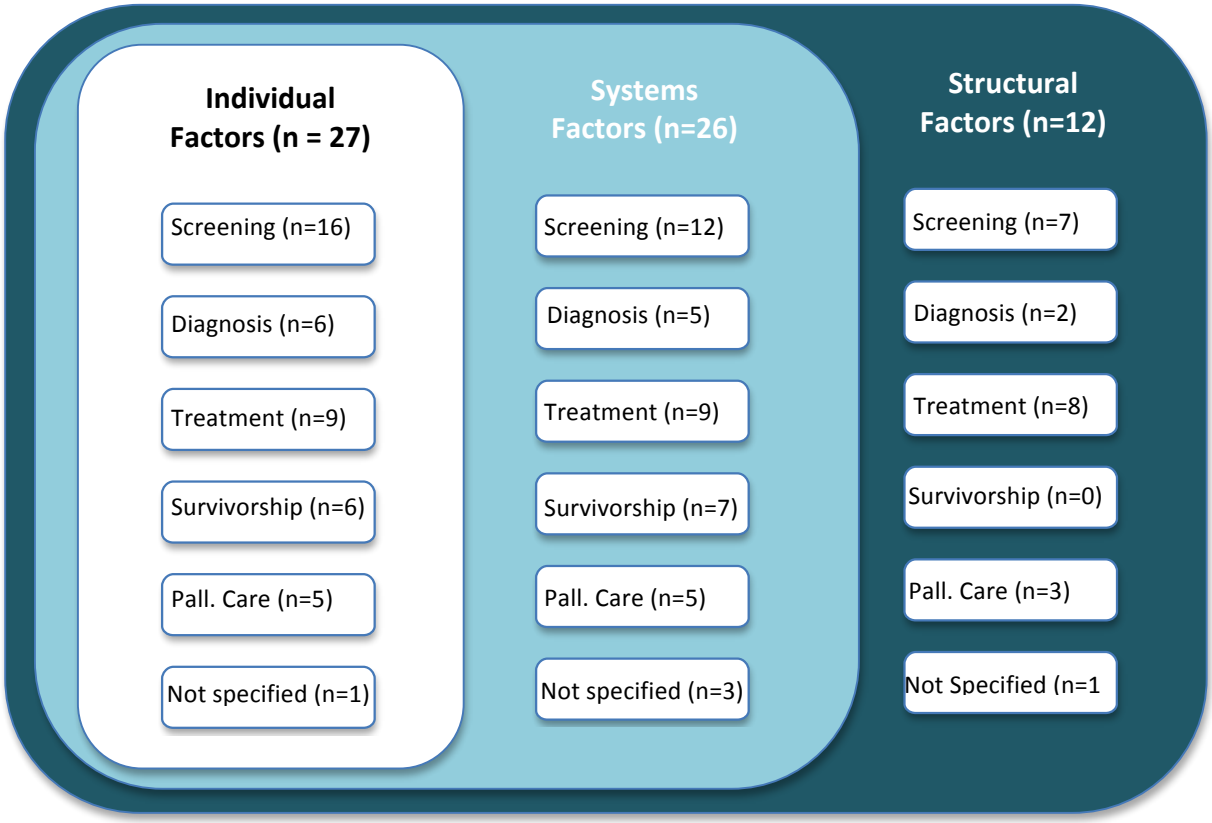
**Barriers to Accessing Cancer Care**

We aimed to answer the research question: *what are the barriers to accessing cancer care for Indigenous peoples in Canada?* To address this question, we extracted the barriers to accessing cancer care as reported in each of the included studies. After extracting the barriers to accessing cancer care cited in each study, we found that barriers could be categorized into three groups: individual factors (issues at the level of the individual patient or healthcare provider (HCP) that impede access to cancer care), systems factors (factors stemming from the healthcare system and its structure), and structural factors (factors that are embedded within and systematically produced political, historical, social or economic structures). We also aimed to answer the research question: *where along the cancer care continuum do these barriers lie?* We conceptualized the cancer care continuum as having five points: screening, diagnosis, treatment, survivorship care, and palliative care. We plotted these groups of factors along with the point of care on the cancer journey trajectory; these results are shown in Figure 2.

**Figure 2:**

*Domain and Type of Barriers Identified*

(NOTE: n = number of *studies* reporting the specified barrier. Some studies reported barriers in multiple domains, and/or in multiple points along the cancer continuum.)




### *Individual Factors*

Individual factors relate to issues at the level of the individual patient or healthcare provider (HCP) that impede access to cancer care, including communication, knowledge and awareness, and experiences of care. Poor communication between patients and HCPs was noted to be a barrier to accessing cancer services (Gould et al., 2009; Loppie & Wien, 2005; Rosicki, 2010; Thomas et al., 2017e). For some patients, experiences of being given the 'run around' by their physician (lack of clear information about their diagnosis and treatment

options) diminished trust within the relationship, reducing access to high quality care (Loppie & Wien, 2005). Other patients have identified that access to cancer screening is reduced when primary care providers do not explicitly recommend cancer screening, or take the time to explain screening procedures (Rosicki, 2010). Barriers to accessing cancer care also reflected the reality of many patients' lives, for example, transportation that was not feasible, convenient or affordable, preventing patients from accessing cancer services (AFN, 2009; Maar et al., 2013; Rosicki, 2010). Given the location of many Indigenous communities, accessing cancer care may require a full day or more of travel, which was too time consuming and not feasible for many patients, particularly when it required the patient to take unpaid time off work (AFN, 2009), leave family and support systems behind (CancerCare Manitoba [CCMB], 2013), or secure reliable and trustworthy childcare (Russell & de Leeuw, 2012). Difficulties accessing financial support to cover the costs of and related to travel, symptom management, and other medications were also identified by patients as barriers to accessing the necessary care (Thomas et al., 2017c, 2017b).

'Knowledge gaps' (terminology used by studies included) among Indigenous patients regarding cancer in general (CCMB, 2013; Loppie & Wien, 2005), the importance of cancer screening (Maar et al., 2013, 2016; O'Brien et al., 2009; Rosicki, 2010), and lower levels of health literacy (Corvus Solutions, 2012; Rosicki, 2010) were reported as barriers to accessing cancer care. Fear and stigma related to cancer were cited in many studies as significant barriers to accessing cancer care (AFN, 2009; Black, 2009; Corvus Solutions, 2012; Hart-Wasekeesikaw, 1996; Loppie & Wien, 2005; Minore et al., 2004; Rosicki, 2010; The Saint Elizabeth First Nations Inuit and Metis Program [SE], 2012). For example, in a report on access to cancer screening, the Assembly of First Nations identified "convictions among First

Nations that cancer is inevitable, and that talking about cancer invites it in", and these beliefs prevent patients from accessing screening services (AFN, 2009, p. 53). In addition, patient fears related to cervical cancer screening procedures (Jensen-Ross, 2006), confidentiality and privacy of appointments (Macdonald et al., 2015), cancer diagnosis and treatment (Lavoie et al., 2016), and palliative care (Hotson et al., 2004) prevented some individuals from accessing cancer care.

Among Indigenous women, a major barrier to accessing cancer care, and cervical cancer screening in particular, was related to histories of trauma and abuse, including sexual and physical abuse, and residential school attendance (Black, 2009; Bottorff et al., 2001; Minore et al., 2004; Russell & de Leeuw, 2012). Negative body image and/or embarrassment were also found to be factors impeding access to cancer services (Black, 2009; Hart-Wasekeesikaw, 1996; Rosicki, 2010; Wakewich et al., 2016). Indigenous women identified that the inability to access a *female* HCP compounded these factors (Black, 2009; Jensen-Ross, 2006; O'Brien et al., 2009; Zehbe et al., 2017). Several studies also noted that among HCP, there is a lack of understanding about the prevalence of trauma, particularly related to residential school attendance, and the impacts of trauma experiences on Indigenous patients (AFN, 2009; CCMB, 2013). Without an understanding of these issues, HCP are unable to deliver services in a trauma-informed manner.

Many studies identified that individual and community experiences of trauma, and the intergenerational impacts of residential school attendance resulted in a general distrust of HCPs, particularly if the care was being providing by non-Indigenous practitioners (AFN, 2009; Bottorff et al., 2001; CCMB, 2013; Jensen-Ross, 2006; Maar et al., 2016; SE, 2012; Thomas et al., 2017c; Wakewich et al., 2016). A "fear of white doctors" and lack of trust in

HCP acts as a barrier to accessing cancer services (AFN, 2009, p. 57)**.** Personal experiences of racism, discrimination, and marginalization all further contributed to patients avoiding accessing cancer care, with the exception of acute health needs (Bottorff et al., 2001; CCMB, 2013; Jensen-Ross, 2006; Macdonald et al., 2015; Rosicki, 2010; Thomas et al., 2017b, 2017c). Closely linked with these barriers was the lack of culturally safe care (respectful, trusting and reciprocal patient-provider relationship), which impeded access to cancer care (AFN, 2009; Black, 2009; CCMB, 2013; Hammond et al., 2017). The Assembly of First Nations notes that "there remains a lack of trust, disempowerment and patient experiences of not being taken seriously by the medical profession…doctors are usually rushed and don't take enough time with patients, leaving the impression that their concerns are unimportant and not allowing time for trust to develop" (2009, p. 58). Culturally safe care is premised on developing respectful, trusting relationships and addressing unequal power relations between patient and HCP, and has been identified as essential to improving accessing to cancer care (AFN, 2009; CCMB, 2013; Hammond et al., 2017; Jensen-Ross, 2006; Maar et al., 2016; Macdonald et al., 2015; O'Brien et al., 2009).

***Systems Factors***

Systems factors are those that stem from the healthcare system and its structure, rather than from an individual or interaction between individuals. Systems factors influencing access to cancer care among Indigenous peoples in Canada include the availability of healthcare providers, the availability and location of healthcare services and the nature of those services, and the interaction between various parts of the system.

The limited availability of HCP created difficulties accessing cancer care, including availability of family physicians, which was seen as essential to gaining entry into the cancer

care system (Black, 2009; Olson et al., 2014; SE, 2012). Difficulty recruiting and retaining HCP in remote geographic locations, and the high turnover of HCP in these locations resulted in reduced availability of HCP (Hotson et al., 2004; Minore et al., 2004; SE, 2012; Wakewich et al., 2016). A shortage of female HCP in Indigenous communities, particularly those trained to conduct cervical or breast cancer screening, was identified as impacting access to cancer care (AFN, 2009; Maar et al., 2013; Wakewich et al., 2016). Maar et al. note that many "First Nations women are shy about their bodies, particularly in medical examinations, and are consequently very uncomfortable with pelvic examinations when performed by male providers" (2013, p. 321). For these women, the inability to access a female healthcare provider means that they likely will not undergo cervical cancer screening.

The availability of healthcare services in general, and cancer services in particular, within Indigenous communities, or within driving distance, was a major barrier to accessing cancer care (Corvus Solutions, 2012; Hammond et al., 2017; Howard et al., 2014; Lavoie et al., 2016; Macdonald et al., 2015; SE, 2012). Cancer screening services (Maar et al., 2013; Mema et al., 2017; Zehbe et al., 2017), diagnostic services (Minore et al., 2004), supportive and/or psychosocial care (Hammond et al., 2017; Olson et al., 2014; Poudrier & Mac-Lean, 2009), inpatient hospital care (SE, 2012) and palliative care (CCMB, 2013; Hordyk et al., 2017; Hotson et al., 2004) were notably insufficient or unavailable in many Indigenous communities. The geographic location of many Indigenous communities (rural or remote) and the lack of cancer care available locally necessitated travelling long distances to access diagnostic services, specialist services, cancer treatment, follow-up care, and sometimes palliative care (Corvus Solutions, 2012; Minore et al., 2004; Olson et al., 2014; Thomas et al., 2017b). The nature of healthcare services and the healthcare system also contributed to

difficulty accessing cancer care: inflexible appointment systems (Macdonald et al., 2015; Zehbe et al., 2017), long wait times (Howard et al., 2014; SE, 2012), and lack of efficient recall systems (Maar et al., 2013) were notable barriers. Zehbe et al. (2017) describe how in some communities, cervical cancer screening is often only offered on certain days of the week; compounding this issue, physicians in small communities are frequently called away to emergencies, and appointments are cancelled and rescheduled. For women who must access financial aid for transportation, arrange childcare, or schedule time away from work, additional barriers to accessing such services become increasingly difficult to overcome. Access to cancer information was also problematic, and was a result of poor or no internet access (Howard et al., 2014), cancer information that was not culturally responsive or relevant (CCMB, 2013; Gould et al., 2009), or information that was not in an Indigenous language (Gould et al., 2009).

The fragmented and complex nature of the Canadian healthcare system created barriers for patients accessing cancer care, and this was exacerbated by jurisdictional issues, particularly among First Nations patients (AFN, 2009). For non-Indigenous and some Indigenous patients, cancer services throughout the trajectory are funded by provincial governments. However, for status First Nations living on reserve, cancer care is accessed in both federal and provincial jurisdictions (see Table 5). Navigating this complex, multi-jurisdictional system was problematic in several of the studies included (Thomas et al., 2017a, 2017b, 2017c, 2017d, 2017e). Moreover, most Indigenous patients do not have a single healthcare provider or a case coordinator to aide in navigating this system (AFN, 2009). Poor communication and coordination between parts of the system (i.e., between cancer agencies and communities, between tertiary care centers and communities) added another layer of

complexity to an already fragmented healthcare system and resulted in patients who were unable to access the care or resources needed (CCMB, 2013; Corvus Solutions, 2012; Olson et al., 2014; SE, 2012).

**Table 5**

*Cancer Services & Jurisdiction*

| Stage in Trajectory | Type of Service | Jurisdiction |
|---|---|---|
| **Screening** | Primary Care Provider<br>Provincial Screening Services | Federal<br>Provincial |
| **Suspicion of cancer** | Primary Care Provider | Federal |
| **Diagnosis (imaging, biopsy)** | Hospital<br>Cancer Center | Provincial |
| **Treatment** | Cancer Center<br>Hospital | Provincial |
| **Follow-up** | Cancer Center<br>Primary Care Provider | Provincial<br>Federal |
| **Palliative Care** | Hospital<br>Palliative Home Care | Provincial<br>Neither |

***Structural Factors***

Structural factors refer to those factors that are embedded within and systematically produced by the political, historical, social and economic structure of a society (McGibbon, 2016; Navarro, 2007). Structural factors impacting access to cancer care among Indigenous peoples in Canada include political structures, such as the federal/provincial division of responsibility for healthcare services to First Nations people and Inuit, socioeconomic conditions, and historical conditions, including residential school experiences and intergenerational historical trauma. For First Nations people and Inuit, these structures – designed by non-Indigenous governments for non-Indigenous Canadians – actually contribute to inequities in access to healthcare between Indigenous and non-Indigenous people.

Socioeconomic factors such as poverty (AFN, 2009; Black, 2009; Corvus Solutions, 2012; SE, 2012), lack of stable and affordable housing, food insecurity, family violence and suicide (Corvus Solutions, 2012) discouraged patients from seeking care or affected their ability to access cancer care in other ways. For example, MacDonald et al. describe how as a result of these structural factors, patients become "focused on daily survival and making ends meet", and are not able to address the need for self-care, including cancer screening (Macdonald et al., 2015, p. 84). Lack of resources for medical travel (AFN, 2009; Black, 2009; Bottorff et al., 2001; Lavoie et al., 2016; Macdonald et al., 2015), and childcare (Black, 2009; Bottorff et al., 2001; Macdonald et al., 2015) also create barriers to accessing cancer care, and are further exacerbated when resources to support transportation and other medical costs are difficult to access (Lavoie et al., 2016; SE, 2012). Several studies noted that although funding is provided to status-First Nations and Inuit for medical travel through the Medical Transportation Policy (under the Non-Insured Health Benefits program [NIHB]), the policy is rigid and does not cover travel for certain services, including cancer screening (AFN, 2009; Lavoie et al., 2016; Loppie & Wien, 2005). Moreover, the policy is applied unevenly and at times capriciously, and is based on budgetary factors and distinctive funding caps not imposed on healthcare services in other programs. The policy is generally seen as not sufficient to meet the healthcare needs of Indigenous people nor erase the unequal health status of Indigenous people in the foreseeable future (Allec, 2005; Jackson Pulver et al., 2010; Lavoie et al., 2015).

Jurisdictional ambiguities or disputes were cited in several studies as creating barriers to accessing cancer care (AFN, 2009; Hotson et al., 2004; Lavoie et al., 2016). For status FN and Inuit, some healthcare services are funded and/or provided by the federal government, and others are funded and provided by the provincial government; for all other Canadians, all

healthcare services are funded and delivered by the provincial government (see 'Background'). As a result, many status FN and Inuit must cross invisible jurisdictional 'borders' to access different cancer services, with tangible effects their access to services and healthcare experiences. Differential access to services (including pain and symptom management medications and palliative care) based on jurisdictional responsibility (i.e. federal versus provincial) resulted in reduced access to these services in some First Nations communities (Hotson et al., 2004; Lavoie et al., 2016; SE, 2012). For example, neither palliative care services or supplies are funded by the federal government for FN living on-reserve, yet provincial palliative care services cannot be delivered on-reserve due to its federal jurisdiction. In some FN communities (reserves), palliative care services are pieced together to meet community member needs, however, palliative care remains unavailable in many of these communities (SE, 2012).

Factors embedded in historical structures, such as the residential school system and geographical location of Indigenous communities, were also identified as having ongoing, residual impacts on access to cancer care. One study noted that the colonial legacy of paternalism, in which Indigenous women were told to let others make decisions for them, resulted in women who were not able to be proactive in accessing healthcare in general, and cancer screening in particular (Black, 2009). Historical and intergenerational trauma stemming from residential school attendance was noted to increase mistrust of HCP and healthcare institutions, which resulted in patients who avoided or delayed accessing cancer care (Jensen-Ross, 2006; Maar et al., 2013; Rosicki, 2010; SE, 2012).

## Discussion & Implications

Among the 36 studies eligible for our scoping review to identify barriers to accessing cancer care among Indigenous peoples in Canada, we noted a significant difference in the number of studies identifying individual factors (n=27) and systems factors (n=26) in comparison to those identifying structural factors (n=12). Certain barriers to accessing cancer care, such as racism and discrimination, although rooted in structural factors, were inconsistently framed in some studies we reviewed as individual and/or systems factors. This suggests an increasing awareness of the impact that racism and discrimination have on access to cancer care, but also reveals a lack of understanding of how, for example, racism at the interpersonal level is linked with systemic and structural racism (Allan & Smylie, 2015). Access to cancer care must be understood as embedded within and impacted by broad structural conditions and determinants of health, which trickle down to influence healthcare systems and individuals. Reducing health inequities and improving access to healthcare means taking action to address those social and structural determinants of health (Commission on the Social Determinants of Health, 2008; Marmot & Allen, 2014). Shifting the attention of researchers, clinicians, and policy makers towards recognizing, addressing, and changing the structural determinants of health would have a significant impact on the health and wellness of First Nations, Metis, and Inuit peoples. In areas related to the wide range of cancer care services, such refocusing could have significant impacts on the lives of Indigenous people and the unequal health status between Indigenous people and other Canadians.

We want to draw attention to colonialism in particular as an important determinant of health among Indigenous peoples (Reading, 2015; Reading & Wien, 2009). Although multiple studies identified structural barriers to accessing cancer care, few studies explicitly identified

colonialism as a structural determinant of health. It is essential to recognize that colonialism acts as a structural determinant of health that shapes and constructs other determinants of health among Indigenous peoples (Reading & Wien, 2009). Many of the structural barriers to accessing cancer care that we identified in this review, including socioeconomic factors (poverty, housing, food security), political factors (jurisdictional ambiguities) and historical factors (residential school systems) can each be linked to colonialism, and this must be recognized and addressed in policy and practice.

In our analysis of Indigenous engagement within the included studies, we found a surprising number of studies in which researchers collaborated with Indigenous peoples throughout the study (n=14), or where Indigenous peoples led the research process (n=3). However, there remained a number of studies in which there was less or no Indigenous engagement in the research process, or where none was reported. While this is concerning on ethical grounds, the lack of engagement may have also impacted the research processes in the studies included – the research questions asked, methods of data collection and analysis, and the conclusions drawn from the research. In particular, this may have contributed to the lack of understanding of how structural and social determinants of health impact Indigenous peoples, as discussed above. Smith argues that researchers involved in Indigenous research must be "committed to producing research knowledge that documents social injustice, that recovers subjugated knowledges, that helps create spaces for the voices of the silenced to be expressed and 'listened to', and that challenges racism, colonialism and oppression" (Smith, 2012, p. 198). Thus, future research would benefit from the inclusion of Indigenous perspectives to critically analyze the determinants of health (Dion Stout, 2015), in addition to critical perspectives that unpack how power shapes and influences structural determinants of

health, and how these, in turn, 'trickle down' to shape social and individual determinants of health (Reading, 2015). We believe that academic publishers should require the disclosure of Indigenous engagement in published studies, as a marker of quality (Beans et al., 2019).

Although we identified barriers to accessing cancer care at each point along the cancer continuum, the level of research focus was disproportionately focused on accessing cancer screening (Figure 2). Specifically, of the included studies, 19 identified barriers to screening, and 12 of these studies focused exclusively on cervical cancer screening. This disproportionate attention to cervical cancer screening may be related to the evidence indicating that incidence of cervical cancer is higher among First Nations women than among non-First Nations women (Chiefs of Ontario & Cancer Care Ontario, 2017; Colquhoun et al., 2010; Decker et al., 2015; Marrett & Chaudhry, 2003; McGahan et al., 2017; Young et al., 2000). Cancer screening is important to ensure cancers are detected in their earliest stage, allowing for treatments that are more effective and less invasive, better quality of life, and improved survival. However, although important, routine cancer screening is only indicated for cervical, breast and colorectal cancers. Timely cancer *diagnosis* is also an important contributor to cancer outcomes: shorter time to diagnosis is associated with improved cancer outcomes (Neal et al., 2015), and cancer stage at diagnosis has a significant impact on survival (CPAC, 2015). Few studies focused on barriers to accessing timely diagnosis and cancer treatment, representing an important gap in the literature.

Finally, although healthcare provider perspectives on accessing cancer care were represented in the studies we reviewed, further analysis revealed that these perspectives were primarily community-based. Nurses provide the bulk of direct patient care in both First Nation communities and oncology settings. Of the studies we reviewed, 7 included nursing

perspectives, but none included oncology nursing perspectives. Nurses, in particular, are well positioned to provide unique insights on inequitable access issues by drawing on their experiences across time, various practice settings, and multiple patients (Thorne, 2016). We suggest that the perspectives of nurses ought to be included in future research examining access to cancer care among Indigenous peoples.

### Strengths & Limitations

A robust search strategy, developed by an academic librarian with significant expertise in the area of Indigenous health, in addition to team members with expertise in Indigenous health research and oncology research contribute to the strength of our study. However, given the complex nature of the concept of access and the various ways in which access is understood, we may have missed studies relevant to our review. The participation of multiple reviewers for study review and selection can also be considered a strength of our study, and is consistent with the recommendations for scoping reviews (Arksey & O'Malley, 2005; Levac et al., 2010). We included only studies conducted within Canada, and given the uniqueness of each country's healthcare system, these results may not be relevant to Indigenous peoples in other countries. However, Indigenous people in higher income countries comparable to Canada (Australia, Aotearoa/New Zealand, the United States) have all experienced similar histories of colonization and oppression, have lower health status and life expectancy than non-Indigenous people, have separately funded systems for health care services, and experience similar geographic and socioeconomic circumstances (Jackson Pulver et al., 2010).

## Conclusion

The results of our scoping study indicate that Indigenous peoples within Canada experience inequitable access to cancer care, which may be reflected in the growing cancer

disparities documented. While access to cancer care among Indigenous peoples is problematic throughout the cancer continuum**,** there has been a strong research focus on access to cancer screening services, and less focus on access to other types of cancer care. Healthcare provider perspectives on inequitable access to cancer care are limited, and nursing perspectives, in particular, are notably absent. Access to healthcare in general, and cancer care in particular, is a complex process, and must be understood within the micro-context of individual lives, the meso-context of the healthcare system, and the macro-context of structural inequities that permeate through the healthcare system and into the day-to-day lives of Indigenous peoples. We argue that future research should focus on all three domains influencing access to cancer care, and examine how these domains interact and influence one another.

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## Sample Search Strategy

**Database:** Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to April 02, 2019>

**Search Strategy:**

1 (exp Indians, North American/ or exp Inuits/ or exp Health Services, Indigenous/ or exp Ethnopharmacology/ or Athapaskan.mp. or Saulteaux.mp. or Wakashan.mp. or Cree.mp. or Dene.mp. or Inuit*.mp. or Inuk.mp. or Inuvialuit*.mp. or Haida.mp. or Ktunaxa.mp. or Tsimshian.mp. or Gitsxan.mp. or Nisga'a.mp. or Haisla.mp. or Heiltsuk.mp. or Oweenkeno.mp. or Kwakwaka'wakw.mp. or Nuu chah nulth.mp. or Tsilhqot'in.mp. or Dakelh.mp. or Wet'suwet'en.mp. or Sekani.mp. or Dunne-za.mp. or Dene.mp. or Tahltan.mp. or Kaska.mp. or Tagish.mp. or Tutchone.mp. or Nuxalk.mp. or Salish.mp. or Stl'atlimc.mp. or Nlaka'pamux.mp. or Okanagan.mp. or Sec wepmc.mp. or Tlingit.mp. or Anishinaabe.mp. or Blackfoot.mp. or Nakoda.mp. or Tasttine.mp. or Tsuu T'inia.mp. or Gwich'in.mp. or Han.mp. or Tagish.mp. or Tutchone.mp. or Algonquin.mp. or Nipissing.mp. or Ojibwa.mp. or Potawatomi.mp. or Innu.mp. or Maliseet.mp. or Mi'kmaq.mp. or Micmac.mp. or Passamaquoddy.mp. or Haudenosaunee.mp. or Cayuga.mp. or Mohawk.mp. or Oneida.mp. or Onodaga.mp. or Seneca.mp. or Tuscarora.mp. or Wyandot.mp. or Aboriginal*.mp. or Indigenous*.mp. or Metis.mp. or red road.mp. or "on reserve".mp. or off-reserve.mp. or First Nation.mp. or First Nations.mp. or Amerindian.mp. or (urban adj3 (Indian* or Native* or Aboriginal*)).mp. or ethnomedicine.mp. or country food*.mp. or residential school*.mp. or ((exp Medicine, Traditional/ or traditional medicine*.mp.) not Chinese.mp.) or exp Shamanism/ or shaman*.mp. or traditional heal*.mp. or traditional food*.mp. or medicine man.mp. or medicine woman.mp. or autochtone*.mp. or (Native* adj1 (man or men or women or woman or boy* or girl* or adolescent* or youth or youths or person* or adult or people* or Indian* or Nation or tribe* or tribal or band or bands)).mp.) and (exp Canada/ or (Canad* or British Columbia or Columbie Britannique or Alberta or Saskatchewan or Manitoba or Ontario or Quebec or Nova Scotia or New Brunswick or Newfoundland or Labrador or Prince Edward Island or Yukon Territory or NWT or Northwest Territories or Nunavut or Nunavik or Nunatsiavut or NunatuKavut)).mp. (6891)
2 exp Cancer Care Facilities/ (4972)
3 exp Medical Oncology/ or exp Neoplasms/ or cancer services.mp. (3158451)
4 cancer*.mp. (1640754)
5 neoplasm*.mp. (2657415)
6 oncol*.mp. (156667)
7 2 or 3 or 4 or 5 or 6 (3655052)
8 1 and 7 (308)
9 limit 8 to english language (303)
10 limit 9 to yr="1996 -Current" (240)

Modified from: Campbell, Sandy, Marlene Dorgan and Lisa Tjosvold. Filter to Retrieve Studies Related to Indigenous People of Canada the OVID Medline Database. John W. Scott Health Sciences Library, University of Alberta. Rev. March 8, 2016.
http://guides.library.ualberta.ca/ld.php?content_id=14026803
Note: modification was change of Inuit.mp to Inuit*.mp [MeSH is Inuits]

**Table 3**

*Selected Data Charting*

| Author/Year | Study Methodology | Location (Province) | Population of Interest | Sex of Interest | Level of Engagement | Location/*Type* of Barriers | Barriers Identified |
|---|---|---|---|---|---|---|---|
| **Asmis et al. (2015)** | Retrospective | Nunavut | Inuit | None | Not specified | Treatment<br>*Systems* | • Women more likely than men to be referred for treatment to OHCC |
| **Assembly of First Nations (2009)** | Descriptive (Qualitative) | Not specified | FN | None | Lead | Screening<br>*Individual*<br>*Systems*<br>*Structural* | • Education and awareness regarding cancer and screening<br>• Fear of cancer<br>• Transportation/logistics (poverty; coordination/length of travel)<br>• Availability of culturally appropriate screening<br>• Fragmentation of services |
| **Black (2009)** | Descriptive (Qualitative) | British Columbia | FN | Women | Not specified | Screening<br>*Individual*<br>*Systems*<br>*Structural* | • Poverty<br>• Lack of culturally safe care<br>• Legacy of paternalism<br>• Body shyness/privacy concerns<br>• Cervical cancer screening not a priority<br>• History of abuse<br>• Too few physicians or nurses |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | • Fear of cancer |
| **Bottorff et al. (2001)** | Case study | Not specified | FN | Women | Not specified | Screening<br>*Individual*<br>*Systems*<br>*Structural* | • Experiences of racism, discrimination and marginalization from healthcare services<br>• Distrust in HCP or services<br>• Feelings of vulnerability related to history of abuse<br>• Logistical (proximity of clinic to public transportation, money for transportation, availability of childcare)<br>• Clinic only focusing on screening |
| **CancerCare Manitoba (2013)** | Descriptive (Qualitative) | Not specified | FN | None | Not specified | Screening<br>Diagnosis<br>Treatment<br>Survivorship<br>Palliative Care<br>*Individual*<br>*Systems* | • Knowledge gaps<br>• Lack of/irregularity of primary care<br>• System logistics (difficulty getting patients into 'front end' of system; poor coordination of services)<br>• Geography (accessing care = leaving family/support behind including children)<br>• Lack of culturally safe care<br>• Transportation |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Corvus Solutions (2012)** | Descriptive (Qualitative) | Nunangat* | Inuit | None | Consult | Not specified<br>*Individual*<br>*Systems*<br>*Structural* | • Geographic distance between communities and cancer services<br>• Fear of cancer; fear of separation from family/community<br>• Socioeconomic stressors<br>• Logistics (lack of integrated/standardized tracking for test results; gaps in communication between HCP)<br>• Low levels of awareness and health literacy |
| **Gould et al. (2009)** | Descriptive (Qualitative) | Ontario | FN | Women | Not specified | Treatment<br>*Individual*<br>*Systems* | • Local availability of care; long wait times<br>• Distance from care required travel that was lengthy, dangerous<br>• Emotional support services rarely available, and not available in languages other than English<br>• Poor access to post-treatment information<br>• Difficulty accessing financial support post-treatment |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Hart-Wasekeesikaw (1996)** | Ethnography | Not specified | FN | None | Lead | Screening<br>*Individual* | • Cultural values of modesty, coupled with women's' embarrassment regarding their bodies<br>• Pervasive fear and silence regarding cancer within First Nations communities |
| **Hammond et al. (2017)** | Participatory (Qualitative) | Not specified | FN | Women | Consult | Survivorship<br>*Individual*<br>*Systems* | • Supportive (psychosocial) care not available locally<br>• Follow-up care specific to cancer not available locally<br>• Lack of respectful care |
| **Hordyk et al. (2017)** | Focused ethnography | Nunavut | Inuit | None | Not specified | Palliative<br>*Systems* | • Very limited availability of end-of-life care locally |
| **Hotson et al. (2004)** | Descriptive (Qualitative) | Manitoba | FN | None | Not specified | Palliative<br>*Individual*<br>*Systems*<br>*Structural* | • Staffing issues<br>• Lack of supports for palliative care in community<br>• Lack of inpatient care for those requiring hospital admission<br>• Lack of support/training for family to participate in palliative care at home<br>• Jurisdiction/bureaucracy<br>• Patient and/or family fears regarding palliative care |

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|---|---|---|---|---|---|---|---|
| **Howard et al. (2014)** | Descriptive (Qualitative) | British Columbia | FN | None | Inform | Survivorship<br>*Individual*<br>*Systems* | • Little medical care available locally; long wait times<br>• Distance from care required lengthy/dangerous travel<br>• Emotional support services rarely available; only available in English<br>• Poor access to post-treatment information<br>• Difficulty accessing financial support post-treatment |
| **Jensen-Ross (2006)** | Focused ethnography | Alberta | FN | Women | Collaborate | Screening<br>*Individual*<br>*Systems* | • Historical/social influences (residential school attendance; mistrust of HCP; discrimination)<br>• Physical/psychological factors (discomfort with male HCP; psychologically intrusive)<br>• "Readiness for change" |
| **Lavoie et al. (2016)** | Interpretive (Qualitative) | Manitoba | FN | None | Collaborate | Diagnosis<br>Treatment<br>Palliative<br>*Individual*<br>*Systems*<br>*Structural* | • Fragmented care<br>• Logistical (transportation, affordable food/housing, lengthy travel)<br>• Having health concerns diminished or dismissed when cancer suspected |

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|---|---|---|---|---|---|---|---|
| | | | | | | | • Limited healthcare services locally<br>• Fear/uncertainty regarding healthcare away from home<br>• Difficulty accessing resources to support access to care |
| **Loppie & Wien (2005)** | Descriptive (Qualitative) | Nova Scotia | FN | None | Lead | Diagnosis<br>Treatment<br>*Individual*<br>*Structural* | • Lack of cancer knowledge<br>• Fear of cancer<br>• Difficulty with communication<br>• Transportation during diagnosis and treatment |
| **Maar et al. (2013)** | Participatory (Qualitative) | Ontario | FN | Women | Collaborate | Screening<br>*Individual*<br>*Systems*<br>*Structural* | • Shortage of HCP trained to do cervical cancer screening<br>• No screening recall system<br>• No screening available locally<br>• Transportation/travel inconvenient or not feasible<br>• Lack of awareness of cervical cancer and screening<br>• Colonial legacy (residential school experiences, racism, |

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|---|---|---|---|---|---|---|---|
| | | | | | | | distrust of healthcare institutions) |
| **Maar et al. (2016)** | Participatory (Qualitative) | Ontario | FN | Women | Collaborate | Screening<br>*Individual* | • Women unfamiliar with cervical cancer screening (rationale for or value of)<br>• Lack of trusting relationships with HCP |
| **MacDonald et al. (2015)** | Participatory (Qualitative) | Not specified | FN | Women | Collaborate | Screening<br>*Individual*<br>*Systems*<br>*Structural* | • Discrimination, racism, stereotyping<br>• Socioeconomic status<br>• Other responsibilities (work, school, home, community)<br>• Fears about confidentiality and privacy<br>• Lack of services, interpreters, timely appointments, transportation |
| **Mema et al. (2017)** | Intervention | Alberta | FN<br>Métis | Women | Not specified | Screening<br>*Systems* | • Geographical location of communities (rural, remote) |
| **Minore et al. (2004)** | Descriptive (Qualitative) | Ontario | Not specified | None | Collaborate | Screening<br>Diagnosis<br>Treatment<br>*Individual*<br>*Systems* | • Geographical location<br>• Staffing shortages<br>• Histories of abuse/residential school experiences<br>• Cancer awareness and stigma |
| **O'Brien et al. (2009)** | Focused ethnography | Not specified | FN | Women | Collaborate | Screening<br>*Individual* | • Screening performed by a male HCP |

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|---|---|---|---|---|---|---|---|
| | | | | | | | • Body shyness/embarrassment<br>• Little knowledge/understanding of cervical cancer/screening; fear of potential consequences |
| **Olson et al. (2009)** | Mixed methods | British Columbia | FN | None | Not specified | Survivorship *Systems* | • Geography<br>• "Disconnect" between specialists and community HCP<br>• Poor access to GPs and supportive/survivorship care locally |
| **Poudrier et al. (2009)** | Descriptive (Qualitative) | Saskatchewan | FN | None | Collaborate | Survivorship *Individual Systems* | • Geography (no access to breast cancer survivorship support groups because of remote location)<br>• Not culturally safe or relevant |
| **Rosicki (2010)** | Descriptive (Qualitative) | British Columbia | FN | Women | Inform | Screening *Individual Systems Structural* | • HCP who were judgmental/disrespectful<br>• Poorly explained screening procedures<br>• GPs not recommending screening<br>• Patient factors (shame/embarrassment, fear of cancer, negative body image, lack of transportation, illiteracy) |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | • Distrust of HCP/system<br>• Intergenerational trauma, childhood sexual abuse<br>• Lack of info/education regarding breast health/screening |
| **Russell & de Leeuw, (2012)** | Descriptive (Qualitative) | British Columbia | FN<br>Métis | Women | Collaborate | Screening<br>*Individual* | • Experiences of trauma/victimization<br>• Feelings of disempowerment (health concerns ignored/dismissed)<br>• Lack of reliable or affordable transportation<br>• Lack of access to reliable, trustworthy childcare<br>• Overwhelming life circumstances |
| **Saint Elizabeth First Nations, Inuit and Métis Program (2012)** | Mixed methods | Not specified | FN | None | Collaborate | Screening<br>Diagnosis<br>Treatment<br>Palliative Care<br>*Individual*<br>*Systems*<br>*Structural* | • Availability of healthcare services locally<br>• Availability of transportation<br>• Availability of HCPs locally<br>• Fear/mistrust of healthcare system/HCP<br>• Historical trauma<br>• Fear/stigma of cancer<br>• Lack of culturally sensitive care |

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|---|---|---|---|---|---|---|---|
| | | | | | | | • Jurisdictional differences in healthcare coverage<br>• Lack of communication between cancer programs<br>• Palliative care not funded in FN communities<br>• Telehealth not available or unreliable<br>• "Bureaucracy" and long wait times for diagnostics/specialists |
| **Tatemichi et al. (2002)** | Survey | New Brunswick | FN | Women | Not specified | N/A | • No barriers identified |
| **Thomas & Gifford (2017a)** | Participatory (Qualitative) | Ontario | FN | None | Involve | Not Specified *Systems* | • Navigating the complex healthcare system<br>• Language barriers |
| **Thomas & Gifford (2017b)** | Participatory (Qualitative) | British Columbia | FN | None | Involve | Treatment Survivorship *Individual Systems* | • Lack of HCP within communities or driving distance<br>• Geography (need to travel long distances for cancer treatment)<br>• Navigating complex system<br>• Difficulty accessing financial support to pay for treatment-related costs<br>• Discrimination from HCP |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Thomas & Gifford (2017c)** | Participatory (Qualitative) | Quebec | FN | None | Involve | Treatment *Individual Systems* | • Navigating complex system<br>• Financial costs (travel, medications)<br>• Racism/discrimination from HCP |
| **Thomas & Gifford (2017d)** | Participatory (Qualitative) | Ontario | FN | None | Involve | Not Specified *Systems* | • Navigating complex system |
| **Thomas & Gifford (2017e)** | Participatory | Ontario | FN | None | Involve | Diagnosis Treatment Survivorship *Individual Systems* | • Poor communication with HCP<br>• HCP relationships – conflict and discrimination<br>• Navigating complex system |
| **Thomas-Maclean et al. (2008)** | Descriptive (Qualitative) | Saskatchewan | Not Specified | Women | Lead | N/A | • No barriers identified |
| **Wakewich et al. (2016)** | Participatory (Qualitative) | Ontario | FN | Women | Collaborate | Screening *Individual Systems* | • Body shame coupled with invasive nature, stemming from colonial legacy<br>• Lack of trusting relationship with HCP<br>• Preference for female HCP<br>• High turnover of HCP (subsequent lack of trusting relationship with HCP) |
| **Zehbe et al. 2016** | RCT | Ontario | FN | Women | Collaborate | N/A | • No barriers identified |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Zehbe et al., 2017** | Participatory (Qualitative) | Ontario | FN | Women | Collaborate | Screening *Individual Systems* | • Distance of screening services from women<br>• Difficulties in arranging travel<br>• Inflexibility in scheduling appointments<br>• Preference for male HCP |

*Nunangat refers to the homeland of the Inuit people, and includes the four regions of Nunavut, Nunavik (located within the Canadian province of Quebec), Nunatsiavut (located within the Canadian province of Newfoundland & Labrador), and the Inuvialuit Settlement Region.

## Chapter 3: Preamble

Chapter 3 was the second step taken towards critically examining access to healthcare among Indigenous Peoples. Here I turn the focus onto exploring nurses' roles in facilitating access to healthcare. My interest in the specific role of nurses developed through my explorations of the concept of healthcare access through a postcolonial lens, which taps into the relational dimensions of healthcare access, and in particular, considering healthcare access through the lens of cultural safety (Horrill et al., 2018). As I immersed myself in the literature, I became increasingly familiar with the work of Browne and colleagues, who have used the frameworks of cultural safety and trauma- and violence-informed care to develop an organizational intervention to improve health equity and healthcare access (Browne et al., 2015). Based on my own experiences as a clinical oncology nurse, and my personal learning as a doctoral student, I began to question how individual nurses could apply these ideas to improve access to healthcare, even if they practiced in organizations that lacked an explicit commitment to health equity.

In this paper I explore healthcare access through the lenses of cultural safety and trauma- and violence-informed care and conceptualize barriers to accessing healthcare in three domains: structural, interpersonal and intrapersonal. I then build upon an existing framework of equity-oriented care for primary healthcare settings (Browne et al., 2012) by proposing strategies to guide nurses in operationalizing cultural safety and trauma- and violence-informed care into nursing practice at the individual level by defining three domains for nursing action: practicing reflexivity, prioritizing relationships, and considering the context. I apply this framework specifically to the context of Indigenous Peoples' access to

healthcare; however, the ideas are relevant to other groups experiencing marginalizing conditions and structural vulnerability.

**Author Contributions**

This paper was published in December 2020, in *Nursing Inquiry*. As the student, I conceptualized the framework, led the team in its development and refinement, and wrote and revised the manuscript. Drs. Schultz, Martin and Lavoie provided critical feedback throughout the development of the manuscript.

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## Abstract

Health equity is a global concern. Although health equity extends far beyond the equitable distribution of *healthcare*, equitable access to healthcare is essential to the achievement of health equity. In Canada, Indigenous Peoples experience inequities in health and healthcare access. Cultural safety and trauma- and violence-informed care have been proposed as models of care to improve healthcare access, yet practitioners lack guidance on how to implement these models. In this paper, we build upon an existing framework of equity-oriented care for primary healthcare settings by proposing strategies to guide nurses in operationalizing cultural safety and trauma- and violence-informed care into nursing practice at the individual level. This component is one strategy to redress inequitable access to care among Indigenous Peoples in Canada. We conceptualize barriers to accessing healthcare as intrapersonal, interpersonal and structural. We then define three domains for nursing action: practicing reflexivity, prioritizing relationships, and considering the context. We have applied this expanded framework within the context of Indigenous Peoples in Canada as a way of illustrating specific concepts and focusing our argument; however, this framework is relevant to other groups experiencing marginalizing conditions and inequitable access to healthcare, and thus, is applicable to many areas of nursing practice.

**Nurses as agents of disruption: Operationalizing a framework to redress inequities in healthcare access among Indigenous Peoples**

Over a decade ago, the World Health Organization's Commission on the Social Determinants of Health highlighted the widespread and growing health inequities within and between countries around the world, noting that inequities are "killing people on a grand scale" (2008, p. 1). Evidence suggests that little has changed since then (Bor et al., 2017; Marmot, 2015; Public Health Agency of Canada, 2018a; World Health Organization, 2019). Health inequities – the systematic differences in health status between various groups – are both generated and maintained by the social structures in which we live (Whitehead & Dahlgren, 2006). These structures refer to the social and structural determinants of health, which include early childhood conditions, income, education, working and living conditions, and access to healthcare (Commission on the Social Determinants of Health, 2008; Raphael, 2016). Inequities, because they are a result of *modifiable* social and structural factors, are thus considered unjust and unfair (Whitehead & Dahlgren, 2006). Although health equity extends far beyond the equitable distribution of healthcare, equitable access to healthcare is well documented as a determinant of health and remains essential to the achievement of health equity (Marmot & Allen, 2014; McGibbon, 2016). While complex and multidimensional, access to healthcare can be understood as the ability to obtain healthcare services (for example, ability to physically access care, or overcome economic barriers) and the delivery of healthcare at the point of care (for example, the acceptability of care or responsiveness of care to meet actual health needs) (Gulliford et al., 2002; Horrill et al., 2018; Levesque et al., 2013). Access to effective healthcare is a basic human right (Whitehead & Dahlgren, 2006).

As a profession, nursing espouses social justice and health equity as core values that have transcended both time and context (Thorne, 2014). As nurses, then, we are compelled to act when we observe *in*equities. Yet many nurses continue to perpetuate inequities through their collective and individual indifference and inaction. Repeatedly, those from within the profession have called on nurses to take action to redress the inequitable distribution of health and healthcare access (Falk-Rafael, 2005; Pauly et al., 2009; Varcoe et al., 2014; Weitzel et al., 2020). We echo these calls and stand alongside nurses working to address these inequities. However, for those nurses who have not (yet) flexed their political and advocacy muscles, calls to disrupt systems and structures may seem overwhelming. Moreover, although nursing is closely aligned with social justice and health equity values, direction on incorporating these values in practice is lacking (Varcoe et al., 2014).

In Canada, the context from which we write, Indigenous Peoples experience significant health and social inequities, including lower life expectancy, higher rates of suicide and some chronic diseases, lower levels of income, higher unemployment rates, and inequitable access to healthcare (Public Health Agency of Canada, 2018a; Smylie & Firestone, 2016; United Nations Permanent Forum on Indigenous Peoples, 2015). Cultural safety has been proposed as one model of care to improve access to healthcare for Indigenous Peoples (Health Council of Canada, 2012; Papps & Ramsden, 1996), in addition to other models such as trauma- and violence-informed care (TVIC) (Public Health Agency of Canada, 2018b) and equity-oriented care (of which cultural safety and TVIC are included as components) (Browne et al., 2012; Browne et al., 2015). Emerging evidence suggests that these models, implemented at the organizational level, are effective in improving access to care, patient experience, and health outcomes (Ford-Gilboe et al., 2018). Although models

targeting systems and structural approaches are critical in addressing inequitable access to healthcare (Ford-Gilboe et al., 2018), nurses who want to address these issues yet practice in organizations that do *not* support such models, may be at a loss for what to do. Moreover, while models such as cultural safety have benefitted from strong conceptual development, they lack guidance for implementation in practice (Brooks-Cleator et al., 2018).

In this paper, we aim to address this gap by operationalizing cultural safety and TVIC at the individual level. We build on the framework by Browne and colleagues (Browne et al., 2012; Browne et al., 2015; Ford-Gilboe et al., 2018), who have conceptualized cultural safety and TVIC as key dimensions of equity-oriented healthcare targeted at the organizational level, by describing a framework that is specifically tailored to guide *individual nurses*. This framework was developed as part of the lead author's (TH) doctoral work, in which the objective was to analyze how cultural safety and TVIC could inform our understanding of healthcare access inequities, and how these perspectives could be applied to improve healthcare access. The framework was developed through a critical review of the literature, and critical reflection and dialogue between the authors (one of whom [JL] has played a key role in the development, implementation and evaluation of equity-oriented care at the institutional level). As authors, we bring extensive experience working with Indigenous Peoples within the context of nursing practice and academic research which has informed our framework; we write from the perspective of white settlers (who have wrestled with how to implement the concepts we discuss) to those who have similar privilege and socio-historical positioning. We begin with a review of the current literature on inequitable healthcare access among Indigenous Peoples through the lens of cultural safety and TVIC, highlighting three domains for nursing action. We then present a framework to guide individual nurses in

integrating cultural safety and TVIC into nursing practice with the goal of disrupting the status quo and redressing inequitable access to care among Indigenous Peoples in Canada. While inequitable access to healthcare is a concern for Indigenous Peoples worldwide and many other groups experiencing structural vulnerability, we have applied our framework within the context of Indigenous Peoples in Canada as a way of focusing our discussion and illustrating our ideas.

**The Context of Nursing Practice in Canada**

In Canada, nurses constitute the largest group of healthcare professionals, the majority of whom are registered nurses (RNs) (Canadian Nurses Association, 2015). Nurses are educated at varying levels, however, an undergraduate degree in nursing is now required for entry to practice for RNs in most of Canada (Canadian Nurses Association, 2015). Increasingly, nurses are part of interdisciplinary healthcare teams and practice in diverse settings, including hospitals, long-term care facilities, communities, workplaces, schools, governments and specialty settings, with 90% of nurses working in direct patient care roles (Canadian Institute for Health Information, 2019; Canadian Nurses Association, 2015). RNs, nurse practitioners (NPs) and registered psychiatric nurses are self-regulated and practice autonomously in Canada; the specific types of care provided, and clinical decisions made largely depend upon the practice area and institution of employment. Researchers have noted, however, that as a corporate model of healthcare has gradually taken root within Canada (with its emphasis on cost reduction and ‘efficiency’), the conditions of nurses’ work have deteriorated (Varcoe & Rodney, 2009). Cost constraint measures have resulted in increased nursing workload, insufficient staffing, forced overtime, and reduced quality of care and patient outcomes (McGibbon & Lukeman, 2019; Varcoe & Rodney, 2009). Furthermore,

corporatization of healthcare has also meant loss of clinical nursing leadership, and fewer opportunities to impact decision-making at the institutional or policy level (Varcoe & Rodney, 2009). Nonetheless, although there are constraints to nurses' work, they do have agency to shape their practice. Given the diversity of nursing practice and the prevalence of nurses within the Canadian healthcare system, many nurses encounter Indigenous patients in their work, and have opportunities to incorporate cultural safety and TVIC frameworks into their everyday practice.

## Cultural Safety and Trauma- and Violence-Informed Care

Cultural safety and TVIC have gained traction within nursing as frameworks that focus on relational approaches to care – that is, grounded in understanding the importance of patient-provider relationships to health and healthcare, and viewing patients within the context of their lives (Brooks-Cleator et al., 2018; Browne et al., 2016). In the following section, we provide a brief conceptual overview of cultural safety and TVIC.

### Cultural Safety

Conceptualized by Māori nurse Irihapeti Ramsden in the late 1980s, and refined during the 1990s, cultural safety grew out of the recognition that the attitudes of nurses, often the first healthcare professional that patients encounter, play a significant role in a patient's willingness to seek healthcare (Papps & Ramsden, 1996; Ramsden, 2002). Although in clinical settings culture is often understood as ethnicity, Ramsden defines 'culture' broadly, as any person or group that differs from the nurse in any way, including by way of socioeconomic status, gender, age, ethnic origin, sexual orientation, (dis)ability, or religion (Ramsden, 2002). With this understanding of 'culture', cultural safety becomes relevant to every nursing interaction (Papps & Ramsden, 1996).

Understanding power, and how it operates within healthcare encounters, is an essential component of cultural safety (Hartrick Doane & Varcoe, 2015; Papps & Ramsden, 1996). Papps and Ramsden (1996) argue that *all* healthcare relationships are power-laden *and* unequal. Cultural safety draws attention to unequal power relationships and demands that nurses think about and recognize that power is operating in every encounter (De Souza, 2015; Papps & Ramsden, 1996), while also working to establish nurse-patient relationships that are built on trust and collaboration (Ramsden, 2002).

At the core of cultural safety is a shift away from cultural 'difference' as the root of health inequities, and opening space to consider the culture of healthcare and healthcare providers as potential reasons for and sites of transformation (Browne et al., 2016; De Souza, 2015). This reflexive turn from outward to inward challenges nurses to examine the beliefs, values, and assumptions held about the 'other', and how these might play out in nursing practice (De Souza, 2015; Gerlach, 2012; Papps & Ramsden, 1996). Reflexive processes extend beyond assessing one's own attitudes, beliefs, and assumptions, and the ways in which these influence the nurse-patient relationship, to also consider the context and structures in which the patient, nurse, and healthcare environment are situated (Hartrick Doane & Varcoe, 2015). Cultural safety directs an examination not only of power imbalances within healthcare relationships, but also those that are structural, and embedded within social, political and economic institutions (Reimer Kirkham et al., 2002).

**Trauma- and Violence-Informed Care**

Trauma, broadly defined as an "experience that overwhelms an individual's capacity to cope", includes both negative experiences and responses to those experiences (Canadian Centre on Substance Abuse, 2014, p. 1). Trauma is most often conceptualized as

interpersonal, including experiences such as sexual or physical abuse, intimate partner violence, or neglect, but can also include events such as war or natural disasters (Canadian Centre on Substance Abuse, 2014; Elliott, Bjelajac, Fallot, Markoff, & Reed, 2005). Within the context of Indigenous health, historical trauma, defined as "multiple emotional and psychological wounding experiences", is also an important consideration (Freeman, 2018, p. 45). In Canada, the residential school system, in which Indigenous children were forcefully removed from their homes and subjected to physical, emotional and sexual abuse, is only one of a series of oppressive policies that resulted in historical and intergenerational trauma (Freeman, 2018). Accessing healthcare services can be re-traumatizing for survivors; in particular, interpersonal dynamics and physical examinations can trigger memories of trauma and prevent survivors from accessing healthcare (Elliott et al., 2005; Reeves, 2015). Evolving in the early 2000's out of work with those experiencing mental health problems, substance abuse and physical trauma, *trauma-informed care* is an approach that recognizes the impact of trauma in an individual's life, and supports an understanding of trauma in all aspects of care (Canadian Centre on Substance Abuse, 2014; Elliott et al., 2005). Key aspects of trauma-informed care include the development of trusting patient-provider relationships, excellent patient-centered communication, maximizing patient autonomy and minimizing risk of re-traumatization (Elliott et al., 2005; Raja et al., 2015; Reeves, 2015).

Trauma-informed care was further extended to include the concept of structural violence, to become known as trauma- and violence-informed care or TVIC (Browne et al., 2012). Structural violence can be understood as "social arrangements that put individuals and populations in harm's way" (Farmer et al., 2006, p. 1686). Such arrangements are embedded in social structures to the point that they become almost invisible (Farmer et al., 2006). They

are structural because they are systematically produced by political, social and economic institutions; they are 'violent' because they result in injury and illness (Browne et al., 2012; McGibbon, 2016). For example, high rates of poverty seen among Indigenous Peoples in Canada, as a result of historical and current policies (Smylie & Firestone, 2016), constitutes structural violence at the population level. Furthermore, inequitable access to healthcare is both an example of structural violence, and a result of structural violence. A TVIC approach builds upon a trauma-informed care approach to include an understanding of the traumatic and physical effects of structural violence on individuals and populations, with particular attention to the impacts of structural inequity. This emphasis is important within the context of Indigenous health, given the pervasive impacts of historical and intergenerational trauma (Freeman, 2018), and the significant structural inequities experienced by Indigenous Peoples as a population (Adelson, 2005; Smylie & Firestone, 2016). Principles of TVIC build on those identified for trauma-informed care and include the provision of respectful care, recognition of the intersectional nature of violence and inequity, understanding health and social issues in the context of individuals' lives, and reduction of traumatizing healthcare encounters (Browne et al., 2016). Such an approach helps move away from locating health and social problems within individuals and towards locating problems within the structures creating them (Browne et al., 2011).

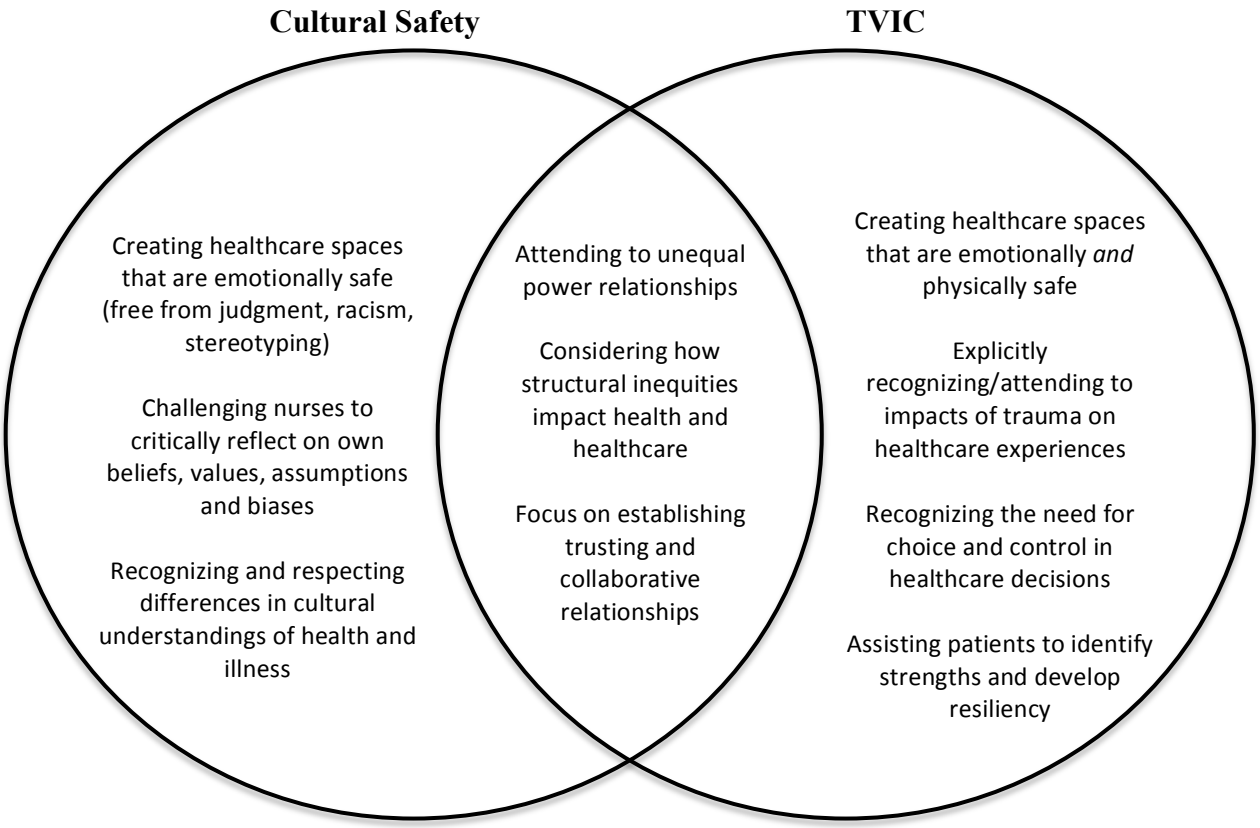
**A Cultural Safety/Trauma- and Violence-Informed Care Approach**

While emerging from different contexts and as distinct concepts, several parallels can be drawn between cultural safety and TVIC (Figure 1). Both prioritize attending to unequal power relations and focus on developing trusting and collaborative relationships. From this perspective, both CS and TVIC are approaches that fit within a relationship-centered care

perspective, which emphasizes that "the nature and quality of relationships are central to health care and the broader health care delivery system" (Beach et al., 2006, p. 3). In addition to relationships, both CS and TVIC consider the way in which structural inequities constrain life opportunities, shaping health and access to healthcare. One subtle yet notable difference is found in the emphasis within TVIC on creating healthcare spaces that are emotionally *and* physically safe and are perceived as comfortable and welcoming (Browne et al., 2016).

**Figure 1**

*Comparing Cultural Safety and TVIC*



## Access to Healthcare for Indigenous Peoples in Canada:

## A Cultural Safety/Trauma- and Violence-Informed Care Perspective

The inequities in access to healthcare experienced by Indigenous Peoples in Canada are significant and well documented (Browne et al., 2011; Cameron et al., 2014; Horrill et al., 2019; Kitching et al., 2020; Lavoie et al., 2016; Tang & Browne, 2008; Tang et al., 2015). While Canada prides itself on its high standards of health and healthcare, not all Canadians enjoy these conditions (de Leeuw & Greenwood, 2011). Indeed, the inequities in access to healthcare experienced by Indigenous Peoples are startling, given Canada's publicly funded and 'equally accessible' healthcare system (Ford-Gilboe et al., 2018).

Barriers to healthcare access are often narrowly understood as stemming from a patient's geographical location (where the patient resides in relation to healthcare services), or as a function of healthcare provider availability (Horrill et al., 2018). However, access to healthcare is a complex phenomenon in which multiple processes and factors intersect and interact (Dixon-Woods et al., 2006; Gulliford et al., 2002; Horrill et al., 2018). Furthermore, CS and TVIC approaches compel us to consider specific relational and contextual influences on access to healthcare (Browne et al., 2016; Papps & Ramsden, 1996), disrupting common conceptualizations of healthcare access which do not consider these influences.

As a way of highlighting the principles of cultural safety and TVIC and organizing our discussion, we have conceptualized barriers to accessing healthcare in three domains: structural, interpersonal and intrapersonal. The beliefs, values and assumptions held by nurses shape their behaviors and interactions with patients and are influenced by discourses within society broadly, and within healthcare and nursing specifically; these can be understood as *intrapersonal* barriers to healthcare access. Pervasive negative healthcare experiences and

nurse-patient relationships can prevent Indigenous patients from accessing high quality healthcare or result in patients who are reluctant or avoid seeking care; these can be understood as *interpersonal* barriers to accessing healthcare. Finally, the policy, legislative, historical, and social conditions that impact access represent *structural* barriers to accessing healthcare. We now turn to a review of existing evidence on access to healthcare for Indigenous Peoples in Canada, situating barriers to access within the three domains of intrapersonal, interpersonal, and structural barriers. Although we draw largely on the Canadian context to enable a nuanced discussion, we use the Canadian experience as an illustration of ideas that are relevant to other healthcare contexts, along with an understanding that inequitable healthcare access among Indigenous Peoples is a global concern.

**Discourses in Nursing as *Intrapersonal* Barriers to Healthcare Access**

Discourses can be understood as ways of "thinking and talking about things" (Springer & Clinton, 2015, p. 92), and these ways of thinking and talking play out in nursing practice in ways that can shape access to care. The principles of cultural safety and TVIC demand that we as nurses critically reflect on the attitudes, beliefs and assumptions we hold. These attitudes, beliefs and assumptions are shaped by discourses operating within the nursing profession (Browne, 2007; McGibbon et al., 2014; Tang & Browne, 2008), and within the broader healthcare and social context in which we live and work (Henry & Tator, 2006; Raphael et al., 2008). Reflecting on how we think and talk as nurses is useful in revealing processes or structures that remain unrecognized or unacknowledged (Springer & Clinton, 2015). Discourses are subject to certain implicit 'rules of engagement' which define and limit what can and cannot be said, and perhaps more importantly, what can and cannot be thought

(Foucault, 1972). Multiple discourses operate within healthcare spaces and nursing practice, and we highlight how some of these impact access to healthcare.

Individualist discourses dominate the health sciences broadly, and have significantly influenced nursing theory, knowledge and practice (Browne, 2001). Individualism considers health as primarily a responsibility of the individual, independent of their social, political, and historical contexts (Browne, 2001; Raphael et al., 2008). When good health is not achieved, patients tend to be blamed for their poor health status, without consideration of contextual influences that may support or constrain health and health behaviors (Hartrick Doane & Varcoe, 2015). Individualist discourses become problematic as they construct patients as 'failing' to take responsibility for their health and therefore less deserving (or undeserving) of healthcare (Browne et al., 2011). Diminishing or dismissing health concerns based on whether we perceive a patient as deserving of care prevents access to high quality nursing care or prevents access to care entirely.

Egalitarian discourses are premised on the notion of a level playing field – that equal life opportunities and access to resources are universally available (Browne, 2001). Research suggests that nurses espouse egalitarian discourses by purporting to treat all patients equally regardless of 'race', 'class' or 'culture', reinforcing the belief that healthcare is equally accessible to all (Browne, 2005; Tang & Browne, 2008). Egalitarian discourses fail to acknowledge underlying structural inequities that construct a playing field that is anything but level (Browne et al., 2016).

Culturalist discourses tend to understand health and social problems as determined by cultural characteristics rather than as a result of social, economic or historical contexts (Browne, 2005). Similarly, racializing discourses categorize and label individuals based on

presumed biological differences and tend to attribute health and social difference to race (Browne et al., 2005; Kirkham & Anderson, 2002). Galabuzzi notes that racialization, an "ideology that ranks some groups as inherently inferior", is embedded in many Canadian institutions, with racial discrimination permeating all sectors of society, including healthcare (2016, p. 405). McGibbon et al. (2014) argue that the bulk of nursing knowledge is in fact based on marginalizing and racializing discourses. The ways in which culturalist and racializing discourses organize nurses' thinking have been observed and documented, with some nurses understanding alcohol addiction, poverty and violence as problems rooted in particular cultural or racial characteristics (Browne, 2005). Moreover, these discourses gloss over the social, political, historical and economic influences on health and healthcare, and perpetuate the 'blame game', whereby Indigenous Peoples are blamed for their poor health (Browne, 2005). Tang and Browne (2008) suggest that access to healthcare is further constrained through racializing processes that act as mechanisms of control, impacting how individuals and their needs are read and interpreted as valid by nurses, and whether those needs are met.

This brief discussion illustrates the power of discourse in shaping individual nurses' attitudes, beliefs, and assumptions, and how they impact access to healthcare. Discourses then can be understood as a barrier to healthcare access as situated *within the nurse* – the intrapersonal space. These discourses do not stay within the intrapersonal space, however. They are enacted in everyday healthcare interactions, and color the space between nurses and patients, dampening the potential for trusting relationships.

**Indigenous Healthcare Experiences as *Interpersonal* Barriers to Healthcare Access**

Grounded in a relational care approach, cultural safety and TVIC approaches highlight the importance of the nurse-patient relationship when considering access to healthcare. Among Indigenous Peoples in Canada, negative experiences with healthcare providers, rooted in racism, persist across time and space, and constitute a significant barrier to accessing healthcare (Allan & Smylie, 2015; Cameron et al., 2014; Goodman et al., 2017; Health Council of Canada, 2012; Hole et al., 2015; Kitching et al., 2020; Monchalin et al., 2020; Nelson & Wilson, 2018; Wylie & McConkey, 2019). Canadian scholars have argued that despite social justice ideals, racism has been normalized within nursing, and continues to go unrecognized and unaddressed (McGibbon et al., 2014). Racism at the interpersonal level results in "inadequate or under-treatment of disease, less systematic or vigorous basic care, less access to quality care, and negatively impact on patient adherence and satisfaction" (McGibbon, 2016, p. 502).

Beyond racism, discrimination and stereotyping based on social class, physical appearance, and other assumptions (such as alcohol use), are also commonly experienced among Indigenous Peoples and influence access to care (Cameron et al., 2014; Health Council of Canada, 2012; Kitching et al., 2020; MacDonald et al., 2015; Tang & Browne, 2008). Experiences of having health concerns diminished or dismissed entirely (Browne et al., 2011), and of intimidation and harassment when accessing healthcare (Cameron et al., 2014) also impede access to high quality healthcare. Many Indigenous patients experience feelings of fear, anxiety, powerless, and distrust when encountering healthcare providers, all contributing to a reluctance to seek care, delaying care or avoiding care entirely (Browne et al., 2011;

Cameron et al., 2014; Goodman et al., 2017; Health Council of Canada, 2012; Nelson & Wilson, 2018).

The evidence reviewed here suggests that even when healthcare services are available and within reasonable geographical proximity, they can be rendered *socially* inaccessible through interpersonal interactions (Tang et al., 2015). Applying a cultural safety and TVIC approach reminds us that the attitudes and actions of nurses can result in patients feeling demeaned, misunderstood, or socially unsafe. Patients who feel unsafe "will not be able to take full advantage of the primary healthcare service offered and may, therefore, avoid the service until dramatic and expensive secondary or tertiary intervention is required" (Papps & Ramsden, 1996, p. 494). Therefore, we must consider the social space between the nurse and patient (the interpersonal space) as an important component of healthcare access and attend to the barriers that are constructed in this space. Social interactions and healthcare relationships exist within a specific context, however, and we must also consider the various contextual influences on access to healthcare.

### ***Structural*** **Barriers to Healthcare Access**

Cultural safety and TVIC approaches require an examination of the contextual influences that create barriers to accessing healthcare, including geography, legislation, policies, and socioeconomic status. Within Canada, many structural determinants of health and barriers to healthcare access among Indigenous Peoples are rooted in colonialism, social exclusion and racism (Reading, 2015). These barriers are understood as structural when they are power-laden, embedded in political and social institutions, and systematically impact a particular group.

The geographic location of many Indigenous communities is a direct result of

legislation, which previously enabled the Canadian government to forcibly relocate Indigenous Peoples to designated tracts of land in rural or remote areas known as ‘reserves’ (Reading, 2015). Historically, some of these reserve lands were economic hubs where oceans and rivers provided transportation for goods, however these communities were largely bypassed and subsequently isolated when land transportation replaced water transportation. Within these small and isolated communities, low population density and poor land transportation infrastructure make attracting and retaining healthcare providers, and offering comprehensive healthcare services difficult (Lavoie et al., 2016; McGibbon, 2016). Geography intersects with other determinants of health to further reduce access to care and compromise quality of care (Richmond & Cook, 2016). For example, securing transportation from rural or remote locations to larger centers is a barrier at the intersection of geography, socioeconomic status (poverty), and restrictive funding policies such as the Medical Transportation Policy (Cameron et al., 2014; Lavoie et al., 2016; McGibbon, 2016).

Within Canada, legislative frameworks specify that healthcare services are to be delivered by each provincial government to the people of that province. Although these frameworks also specify that Indigenous Peoples, specifically those registered with the federal government of Canada (often referred to as ‘status First Nation’ or ‘registered Indians’ in addition to Inuit) are the purview of the federal government, there are no specifications in regard to provision of healthcare services. The Canadian government provides and/or funds some healthcare services to some Indigenous people (status FN living on-reserve), however, it maintains that these services are provided on compassionate grounds rather than out of a legal responsibility (Lavoie, 2018). A jurisdictional divide is created for many Indigenous Peoples in Canada, who access some care provided by the federal government (primarily public health

and health promotion), and some by the provincial government (i.e., acute care, diagnostics). As a result, many Indigenous Peoples must repeatedly cross invisible and often ambiguous jurisdictional boundaries to access healthcare services, resulting in delayed care and/or logistical fatigue, which can lead to premature abandonment of lifesaving or life prolonging treatment (Lavoie et al., 2016).

**Table 1**

*Summary of Barriers to Healthcare Access*

| **Domain/Location of Barriers** | **Types of Barriers** | **Examples** |
|---|---|---|
| ***Intrapersonal*** (located within the attitudes, beliefs and assumptions of the nurse) | Individualism<br><br>Egalitarianism<br><br>Culturalism<br><br>Racialization | • Blaming individuals for poor health and subsequently assuming they are less deserving of healthcare services<br>• Assuming equal opportunity and access to healthcare services, and assuming poor health is a result of poor effort<br>• Assuming poor health or unhealthy choices (i.e., poor diet) are a cultural trait rather than a result of structural inequity<br>• Assuming poor health or unhealthy choices (i.e., alcohol addiction) are a result of biological or 'racial' characteristics rather than structural inequity<br>• Each of these make establishing trusting relationships between the nurse and patient difficult, impacting equitable healthcare access |
| ***Interpersonal*** (located within the nurse-patient relationship) | Negative healthcare experiences | • Experiences of racism from healthcare providers or anticipation of poor treatment resulting in patients delaying or avoiding healthcare services/providers<br>• Experiences of having health concerns diminished or dismissed by healthcare providers resulting in the inability to access necessary healthcare services |
| ***Structural*** (located within political, social or economic institutions) | Geography | • Rural/remote/isolated location of FN communities makes it difficult to provide comprehensive healthcare services (poor infrastructure, difficulty recruiting/retaining staff); results in lack of |

| | | |
|---|---|---|
| | Legislation/ Jurisdiction | services available<br>• Canadian legislation granting responsibility for FN to federal government and responsibility for healthcare delivery to provincial government; results in jurisdictional ambiguities and disputes about fiscal responsibility for care and complicates/delays access to care |
| | Policy | • Medical transportation policy increasingly rigid, focusing on fiscal accountability vs. maximizing access to healthcare; results in delayed or denial of transportation to access care |
| | Socioeconomic Status | • Lower employment and income rates among FN preclude full access to healthcare services; results in inability to afford transportation, unpaid leave from employment, pharmaceuticals or other treatments not covered under insurance |

Although we have discussed barriers in access to healthcare as situated within multiple domains – within the context of structures, within the nurse-patient relationship, and within nurses themselves – these barriers are not merely additive. Rather, as Richmond and Cook note, barriers to accessing healthcare are *intersecting*, particularly among Indigenous Peoples (Richmond & Cook, 2016). An intersectional perspective provides a lens to see these barriers as interacting, mutually reinforcing and cumulative, acknowledging the complexity of inequitable access to healthcare among Indigenous Peoples. Processes of and decisions about accessing healthcare are complicated, and are not only determined by a patient's physical condition, but are "mediated by a range of complex circumstances, including past experiences with health care, geographic and social boundaries, and people's lived experiences of racialization and marginalization" (Browne et al., 2011, p. 343).

## Using Cultural Safety and Trauma- and Violence-Informed Approaches to Improve Access to Care: A Framework for Individual Nurses

In light of persistent health and social inequities, and the social justice mandate within nursing, we as nurses are called upon to take action (Falk-Rafael, 2005; Pauly et al., 2009; Weitzel et al., 2020). Bearing witness to social injustice and suffering daily, nurses are in a privileged position, along with which comes a moral responsibility for action (Falk-Rafael, 2005; McGibbon & Lukeman, 2019). McGibbon and Lukeman (2019) note that as nurses, "we must necessarily work at the pointy edges of suffering and safety in peoples' lives, and yet go well beyond this suffering to disrupt structures that cause the suffering in the first place" (p. 5). Previous work has conceptualized cultural safety, TVIC and contextually tailored care as key dimensions of equity-oriented healthcare for Indigenous Peoples in Canada (Browne et al., 2016; Ford-Gilboe et al., 2018). This work has targeted healthcare at the systems and institutional levels, aiming to improve health outcomes (Browne et al., 2015; Ford-Gilboe et al., 2018). Building on these ideas, we propose an additional framework that is specifically tailored to guiding individual nurses in applying the concepts of cultural safety and TVIC in nursing practice to strategically address access to healthcare for Indigenous Peoples.

In the preceding discussion, we conceptualized barriers to accessing healthcare as situated in multiple, intersecting domains. Building on this conceptualization, cultural safety and TVIC also illuminate sites for nursing action in these domains to improve healthcare access (Figure 2). A cultural safety and TVIC approach begins by directing a reflexive turn from outward to inward – from a focus on the external conditions of access to a focus on the internal conditions within the nurse – and begins within the individual nurse working to

disrupt discourses that shape attitudes, beliefs, and assumptions and healthcare interactions and thus access to healthcare by *practicing reflexivity*. It then expands outward to *prioritize relationships* by focusing on the nurse-patient relationship and the nature of the healthcare relationships directly affects access to healthcare. Finally, it expands to the level of the environment, to *consider the context* in which the patient is accessing healthcare and draws attention to structural inequities embedded within healthcare and social contexts.

**Countering Intrapersonal Barriers to Healthcare Access: Practicing Reflexivity**

The starting place for cultural safety begins with the self. The First Nations Health Authority (a provincial health authority in the Canadian province of British Columbia) notes that system-wide change begins within each healthcare provider: “the phrase 'it starts with me' signifies how everyone, whether a health care professional, staff, manager, leader, First Nations person or family member, can be a part of achieving the vision for a culturally safe health care system" (First Nations Health Authority, n.d.). 'It starts with me' is a call to critical self-reflection, and within the context of cultural safety, challenges us to examine our own “cultural realities” and attitudes that we bring into practice (Dyck & Kearns, 1995, p. 141).

Critical reflection on what we as nurses are thinking and feeling begins to draw our attention to the discourses that organize and shape our nursing practice and healthcare environments, revealing a potent site for nursing action. Shifting towards a discourse of cultural safety has the potential to disrupt dominant discourses within healthcare contexts and question taken-for-granted assumptions (Browne, 2005; Richardson & MacGibbon, 2010). Further, nurses must learn to recognize the discourses operating within nursing (van Herk et al. 2011) and how these are embedded within broader social discourses. Browne observes:

> A focus on the attitudes or assumptions of *individual* health-care providers overlooks the fact that attitudes and assumptions are deeply entrenched in the dominant culture. Assumptions about Aboriginal peoples or any other group of people do not emerge merely from the misinformed opinions of individual nurses…[but reflect] discourses and assumptions embedded in the dominant society (Browne, 2005, p. 81).

Through this lens, we are reminded of the importance of practicing reflexivity in understanding how our own attitudes, beliefs and assumptions are shaped within the broader social context. We must also reflect on our socio-historical positioning, how that positioning influences how we are perceived as nurses, and how we bring that positioning into nursing practice (Browne et al., 2016). Reflexivity and reflective practice can be fostered through mentorship, mindfulness practices, facilitated reflection (Caley et al., 2017) and could be enhanced with input from Elders and nurses with Indigenous ancestry. Questions to guide nurses in practicing reflexivity are provided in Figure 2.

**Countering Interpersonal Barriers to Healthcare Access: Prioritizing Relationships**

Cultural safety and TVIC both prioritize relationships as central to nursing practice and understanding the impact of relationships on access to healthcare begins to disrupt models of nursing practice that are primarily task-based. Nurse-patient relationships built on trust and acceptance foster access to high quality nursing and healthcare. Walker and Ben-Smith write that *relationship is medicine*, noting that there is "remarkable opportunity for individuals working within the medical system to acknowledge and honor relationships as one of the key medicines for Indigenous peoples" (Walker & Behn-Smith, 2015, p. 252). Hartrick Doane and Varcoe (2015) also note the importance of relationships in fostering access to high quality healthcare:

> Repeatedly, our research has shown that people and families can be supported or discouraged from accessing the health care they need by how nurses practice… any effort a nurse can make to reduce people's fear, anticipation, and experiences of judgment, stigma and discriminatory treatment can improve access (p. 155).

Through the lens of cultural safety and TVIC, we are drawn to an awareness of our positionality and power vis-à-vis our patients (Anderson et al., 2003; Dyck & Kearns, 1995). While discourses within nursing might suggest that nurses are relatively powerless within the broader healthcare setting, we do have a degree of power (although we are not always be aware of it) which is enacted within the context of the nurse-patient relationship (Ramsden, 2002; Tang & Browne, 2008). Power, then, must be *shared* to establish collaborative and mutual relationships (Dyck & Kearns, 1995). Likewise, safety and trust also develop *within relationship*, and are negotiated in every healthcare encounter (Anderson et al., 2003; Reimer Kirkham et al., 2002). As nurses, we are called upon to become more aware of how our actions produce and reproduce health inequities (Browne, 2005, 2007; Tang & Browne, 2008; Tang et al., 2015). Questions to guide nurses in prioritizing relationships are provided in Figure 2.

**Countering Structural Barriers to Healthcare Access: Considering the Context**

Finally, cultural safety and TVIC approaches compel us to consider the environment and context in which patients are situated. Such an approach requires us to understand how structural inequities rather than individual deficits or characteristics, impact access to care (Dyck & Kearns, 1995), and to disrupt the tendency to assess access to healthcare a-contextually. This includes understanding the social, political, historical and economic conditions that "underpin both inequities in access to healthcare and inequities in health

outcomes" (Pauly et al., 2009, p. 122). A cultural safety approach helps us recognize that the current health and social status of Indigenous Peoples in Canada is directly tied to colonialism and opens space to consider its deleterious and ongoing influence (Smye & Browne, 2002). It also challenges us, as nurses, to continuously be alert to how patients are positioned socioeconomically, politically and historically, and the corresponding oppressions within the healthcare system. The importance of considering the patient in context extends far beyond Indigenous Peoples in Canada and is equally relevant to other groups who experience multiple intersecting barriers to accessing healthcare, including those experiencing poverty, issues with mental health and addictions, and other racialized and Indigenous populations globally. While structural inequities may be outside the immediate control or influence of individual nurses, there are ways in which nurses can work to impact positive change.

At the individual level, considering the context requires inquiring into the realities of a patient's day-to-day life, acknowledging structural inequities and conveying an understanding of these inequities to patients to lay the foundation for the development of a trusting relationship (Varcoe et al., 2014). Locating difficulties in accessing healthcare within systems and structures rather than individuals shifts the 'blame' off of the patient (Varcoe et al., 2014). For example, rather than label the patient as 'non-compliant' for 'failing' to attend their appointment, acknowledge and address factors of poverty, transportation, childcare, and clinic hours or location as impacting the patient's attendance at appointments.

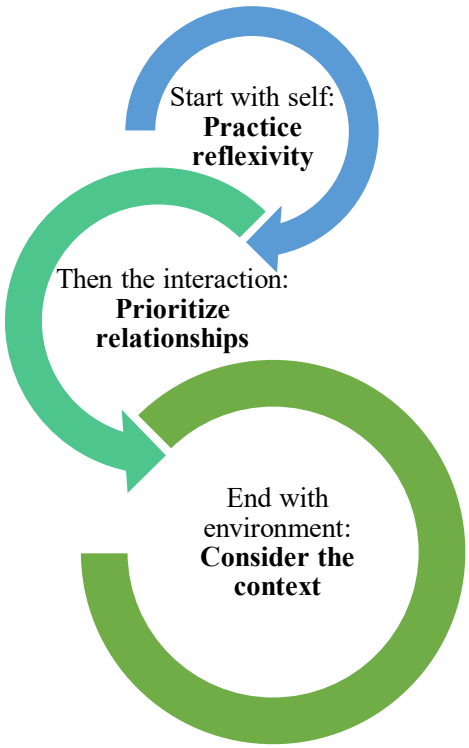
Within the broader healthcare context, individual nurses have a responsibility to advocate for equitable healthcare access. As healthcare professionals, nurses can take advantage of society's interest and investment in the healthcare system by providing education on the structural and social determinants of health and how these impact access to healthcare

(Raphael et al., 2008). Many nurses witness the impacts of structural inequities on individual patients and can speak to the stories of those most impacted by inequity.

Nurses must be able to recognize and call out individual and structural racism (Bailey et al., 2017; Dyck & Kearns, 1995; Thurman et al., 2019). Nurses can also be involved in critically evaluating organizational and governmental policies for their role in shaping access to healthcare and other determinants of health and perpetuating structural racism (Raphael et al., 2008; Thurman et al., 2019). Subsequently, nurses can advocate for policies that attend to structural inequities and support access to healthcare (Raphael et al., 2008; Thurman et al., 2019). Questions to guide nurses in considering context are provided in Figure 2.

**Figure 2**

*A Cultural Safety and Trauma- and Violence-Informed Care Framework for Redressing Inequities in Healthcare Access*



**(Figure 2 Con't)**

**INTRAPERSONAL DOMAIN: PRACTICE REFLEXIVITY**

*First,* start with yourself. Take a critically reflexive approach, shifting the focus inward, and reflect on:

- What attitudes, values and beliefs do you hold towards those who are different than you, both personally and professionally? For example, how do you feel and think about someone who is of a different ethnicity, culture, ability or gender? What may have shaped those attitudes, values and beliefs?
- How are you positioned personally and professionally as a nurse (socially, historically and economically) in relation to the patient(s) and their families that you provide care for?
- How do you think your attitudes, values, beliefs and positionality impact your nursing practice? How might these impact access to healthcare for patients? Consider engaging with a mentor or an online tool to help you identify and challenge the hidden biases that you may have.

**INTERPERSONAL DOMAIN: PRIORITIZE RELATIONSHIPS**

*Next,* shift your perspective to those around you, and critically evaluate how you relate to/with patients and how they relate to/with you:

- How do you relate to patients or families that are different from you? Similar to you? How would a patient rate your interactions? Ask for feedback from a trusted colleague.
- How can you establish trusting, collaborative relationships with patients and families that convey respect and acceptance? Use communication and body language, including basic manners and active listening; use language that is non-judgmental and avoid technical language.
- How can you share in power and vulnerability to establish a partnership with a patient or family rather than a hierarchy? Think about ways you could involve the patient and family in their care.
- What strengths does this patient and/or family have? Consider how you could acknowledge and support them in using these strengths.
- Do you speak out against behaviors among nurses and other healthcare providers that convey negative attitudes or judgment (i.e., eye rolling, labeling patients, etc.)? Seek out colleagues or groups of like-minded healthcare professionals who can support you in your efforts to call out racism and other forms of stereotyping and discrimination.

**STRUCTURAL DOMAIN: CONSIDER THE CONTEXT**

*Finally,* consider where the patient is situated, how context is shaping what is happening in the situation, and how you can draw attention to the structural determinants of health in your practice:

- How is this patient situated historically/socially/economically? Are you aware of the structural determinants of health faced by this patient or group that may be impacting his/her access to healthcare or health? Engage with organizations working with or advocating for structurally disadvantaged groups.
- Can you acknowledge the context of the patient's life or address any of the social or structural inequities experienced by this patient to improve their access to care? Partner with other members of the healthcare team or organizations outside of your workplace.
- Do you understand the historical context of colonialism and its ongoing effects on health and access to healthcare? Participate in circles of reconciliation and ceremony.
- How can you make the clinical or physical space feel safe and welcoming? Solicit feedback from patient advocacy groups.
- What steps can you implement as a nurse and a global citizen to disrupt or dismantle structural inequities? Advocate to elected officials and professional nursing organizations; participate in protests; join or form a committee within your workplace; propose or revise policies within your organization; write an op-ed.

## Limitations

As we have argued in this paper, the significance of cultural safety and TVIC approaches are in their relevance and applicability to much of nursing practice, and how they call on us as nurses to act wherever we are situated. Putting the full responsibility for cultural safety and TVIC on the nurse, however, is problematic (Richardson & MacGibbon, 2010). We must be aware of how nursing practice is itself constrained by contextual and structural influences (Doane & Varcoe, 2007; Richardson & MacGibbon, 2010). Without discounting the agency of individual nurses to implement cultural safety in their practice, Richardson and MacGibbon (2010) note how cultural safety competes with other (and perhaps more powerful) nursing and medical discourses of maintaining order, routine, and efficiency at the expense of relational nursing care. It is also important to acknowledge the distress that can be experienced when nurses understand what 'ought' to be done but cannot, because of time and/or resource limitations and other structural barriers (Anderson et al., 2003). Any attempt at implementing cultural safety and TVIC in practice must consider institutional and discursive constraints, which may limit the effectiveness of such an approach within that context. Finally, we have not yet evaluated or applied the framework: this will be the focus of further research we are planning, and we anticipate some refinement as a result. In addition, although it was informed by our experiences of decades of work with Indigenous Peoples, we did not specifically engage Indigenous Peoples in the development of the framework, which would constitute an important next step.

## Conclusion

Inequities in health and healthcare access, particularly among Indigenous Peoples in Canada, remain a pressing concern. A narrow understanding of access to healthcare is

common within healthcare, and glosses over important structural and relational barriers to access (Horrill et al., 2018). Although the causes of inequitable healthcare access are complex, approaches rooted in cultural safety and TVIC are important in facilitating an understanding of the roots of these inequities – barriers within multiple and intersecting domains that structure inequitable healthcare access. We are reminded that, as an advocacy profession rooted social justice ideals, we as nurses can make significant contributions to ensuring nursing practice is infused with the critical reflexivity necessary for transformational change (Thorne, 2018). Yet social justice cannot be achieved without disrupting the status quo (Kirkham & Browne, 2006). The framework we describe builds upon existing cultural safety and TVIC frameworks to guide individual nurses in integrating cultural safety and TVIC into practice as a way of improving access to care. Considering barriers to healthcare access through the lens of cultural safety and TVIC disrupts assumptions that strategies to improve access can only target systems and structures. Although paramount to engage nurses and patients with Indigenous ancestry to acquire their input and feedback on this expanded framework as an important next step, the strength of the framework we describe is in its emphasis on understanding that how we practice as individual nurses can impact lives and influence how people experience inequities in health and access to healthcare. We *all* have a role to play.

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## Chapter 4: Preamble

Chapter 4 presents the results of the first of two primary research studies included in the thesis. In the first study, a national online qualitative survey of oncology nurses' perspectives on access to oncology care among Indigenous Peoples was conducted, which aimed to provide a 'snapshot' picture of oncology nurses' perspectives. Building on the findings of the scoping review, my aim in this analysis was to consider not only the types of barriers described by nurses (i.e., individual, systems, structural), but also the ways in which they talked about accessing care, with the understanding that their narratives around access to oncology care would influence their views on how they as nurses could impact access to care. Given the conceptual exploration presented in Chapter 3, in which I proposed that nurses could improve access to oncology care through incorporating cultural safety and trauma- and violence-informed care approaches into practice, I was particularly interested in oncology nurses' perspectives on the relational aspects of nursing care with Indigenous Peoples.

### Author Contributions

I conceptualized and designed the study, under the supervision of my advisors. I conducted the data collection and analysis, and wrote and revised the manuscript in consultation with Dr. Schultz. Drs. Schultz, Martin and Lavoie provided critical feedback throughout the development of the manuscript which will be submitted for publication upon completion of the thesis.

## Abstract

Inequities in access to healthcare and oncology care among Indigenous Peoples in Canada are well documented. Access to cancer care is mediated by a range of factors, however, emerging evidence suggests that healthcare providers, including nurses, play a significant role in shaping equitable access to healthcare and cancer care. The purpose of this qualitative study was to critically examine access to oncology care among Indigenous Peoples in Canada from the perspective of oncology nurses. Critical and postcolonial theoretical perspectives informed this study. A multiple-methods design was used, which included an online survey, the results of which are reported here. Oncology nurses were recruited from across Canada to complete the online survey (n=78). An interpretive descriptive methodology guided analysis of participant responses. Findings indicate that nurses were aware of a wide range of barriers faced by Indigenous Peoples when accessing oncology care. Nurses located these barriers primarily at the individual and systems levels. Nurses perceived themselves to function as mediators of access to oncology care, yet their efforts to facilitate access to high quality oncology care were constrained by the dominance of biomedicine within healthcare settings. Oncology nurses' constructions of access to oncology care highlight the embedded narrative of individualism within nursing practice and healthcare discourse, and the relative invisibility of racism as a determinant of equitable access to healthcare among Indigenous Peoples. There is a clear need for oncology nurses to better understand and incorporate a structural determinants of health perspective in practice, education, and research.

# A Critical Exploration of Nurses' Perceptions of Access to Oncology Care Among Indigenous Peoples: Results of a National Survey

Among Indigenous Peoples in Canada, inequitable access to healthcare broadly, and oncology care specifically, have been well documented in Canada (Horrill et al., 2019; Horrill et al., 2020a; Katz et al., 2019; Nader et al., 2017; National Collaborating Centre for Aboriginal Health, 2011; Nguyen et al., 2020; Shah et al., 2003). Although access to oncology care is mediated by a range of factors (service location, provider availability, policies, social determinants of health), nascent evidence suggests that healthcare providers, including nurses, play a significant role in shaping equitable access to healthcare through their interactions with patients (Browne et al., 2015; Browne et al., 2016; Kitching et al., 2020; Wylie & McConkey, 2019). From the perspective of Indigenous patients, experiences of racism, discrimination or judgment on the part of healthcare providers have significant impacts on access to care (Browne et al., 2011; Cameron et al., 2014; Goodman et al., 2017; Tang & Browne, 2008). However, within the context of access to oncology care, the perspectives of these healthcare providers – particularly nurses, who are often the first point of contact for patients and provide the bulk of clinical care – have not been explored (Horrill et al., 2019). In this paper, I discuss the findings of a study that used a postcolonial theoretical perspective to explore oncology nurses' understandings of access to oncology care for Indigenous Peoples, and their perceived role in improving access to oncology care.

## Problematizing our Understanding of Access

Access to care is most commonly understood as a function of the physical (geographical) location of healthcare services (Horrill et al., 2018). Physical access depends on the spatial and temporal distance between healthcare services and those accessing them

(Wilson & Rosenberg, 2004), thus the geographical location of many Indigenous communities (remote, isolated) as a result of colonial government policies contributes to the inaccessibility of healthcare services (National Collaborating Centre for Aboriginal Health [NCCAH], 2011; Shah et al., 2003). The organization and appropriateness of services delivered and whether those services meet actual patient needs must also be considered (Pauly et al., 2009; Wilson & Rosenberg, 2004). Delays in diagnosis or treatment of illness, and unmet health needs such as untreated or under-treated pain, indicate difficulties in accessing high quality, responsive healthcare services (Kitching et al., 2020; NCCAH, 2011; Nelson & Wilson, 2018).

In addition to physical distance, healthcare access is also often depicted as a function of service availability, where increasing services is assumed to improve access to care. This 'technocratic' model of access is highly problematic with little regard for social barriers to accessing healthcare (Tang et al., 2015). A postcolonial perspective highlights several other important considerations beyond physical access (service location and availability), including structural and relational aspects of access. Accessing healthcare requires patients to mobilize social, economic and other resources in pursuit of healthcare services (Pauly et al., 2009; Wilson & Rosenberg, 2004); socioeconomic resources, for example, are a significant determinant of access to healthcare among Indigenous Peoples (NCCAH, 2011; Nelson & Wilson, 2018). Increasingly, evidence points to the need to understand healthcare as a socio-relational space, where access to care is constructed in part through the *interactions* between healthcare providers and patients (Horrill et al., 2018; Tang et al., 2015). Among Indigenous Peoples, these interactions must be seen within the context of broader social and historical circumstances, in which Indigenous Peoples face the ongoing effects of colonialism through

everyday experiences of racism and discrimination (Browne & Fiske, 2001). As a framework for improving access to care among Indigenous Peoples, cultural safety draws attention to unequal relations of power between patients and providers, and challenges nurses to think critically about what they are bringing into each patient encounter (Anderson et al., 2003). A cultural safety perspective suggests that the attitudes of nurses, often the first healthcare professionals encountered, play a significant role in a patient's willingness to access healthcare (Papps & Ramsden, 1996).

**Nurses and Access to Healthcare**

Grounded in the concept of cultural safety and the importance of relationships in determining access to healthcare among Indigenous Peoples, nurses can and do play a significant role. Within the Canadian context, healthcare encounters between nurses and Indigenous patients are shaped by and infused with racism, discrimination, assumptions and popular discourses about Indigenous Peoples, resulting in diminished quality of care and patients' reluctance to access healthcare services (Browne, 2005; Browne & Fiske, 2001; Browne et al., 2011; Cameron et al., 2014; Goodman et al., 2017; Hole et al., 2015; Nelson & Wilson, 2018; Waldram et al., 2006; Wylie & McConkey, 2019). Nurses' assumptions about Indigenous patients impact how patients' needs are understood, and how (or whether) those needs are met (Browne, 2007; Tang & Browne, 2008). This reflects the tendency of nurses practicing within Western contexts to focus on the individual patient, while overlooking the socioeconomic, historical or political context of patients' health and access to healthcare (Browne, 2005; Tang & Browne, 2008). For the most part, nurses are not *intentionally* engaging in behaviors that are harmful, and research suggests that nurses are not necessarily *aware* of how their actions/interactions serve to produce/reproduce inequitable access to care

(Browne, 2005; Tang et al., 2015). Despite this evidence, as a discipline, nursing remains largely silent on issues of racism and structural inequities (Thorne, 2017; Thurman et al., 2019).

**Access to Oncology Care: Physical, Structural & Relational Considerations**

Oncology care can be defined as any health service related to the detection, treatment, or follow-up (including rehabilitation, supportive and palliative care) of cancer, regardless of setting (Horrill et al., 2019). Oncology care is provided by a range of healthcare providers, including primary care physicians, specialist physicians or surgeons, nurses (i.e., oncology nurses, nurse navigators), and allied healthcare providers (i.e., dieticians, speech-language pathologists, social workers). In Canada, responsibility for cancer control, including the planning and oversight of cancer services is given to provincial cancer agencies; the delivery of cancer services occurs through provincial, regional and community cancer centres, tertiary care centres, and primary care settings.

Accessing oncology care presents many challenges for Indigenous Peoples in Canada. Access to primary care (essential to accessing the oncology care system) is limited (Black, 2009; Olson et al., 2014; The Saint Elizabeth First Nations Inuit and Metis Program [SE], 2012) and, as a result of geographical location, cancer-specific services are rarely available in Indigenous communities (Galloway et al., 2020; Hammond et al., 2017; Lavoie et al., 2016; SE, 2012). Cancer screening programs are generally not accessible to First Nations peoples living on-reserve as these programs are under provincial jurisdiction, with the exception of cervical cancer screening, typically provided by primary care providers (Lavoie et al., 2016). Patients must often travel long distances to access oncology care, relying on transportation that may not be feasible nor affordable (Assembly of First Nations, 2009 [AFN]; CancerCare

Manitoba [CCMB], 2013; Galloway et al., 2020). Although transportation funding for medically necessary health services is provided to status First Nations and Inuit through Non-Insured Health Benefits, and in some cases, to non-status First Nations and Métis through provincial programs, there continues to be difficulties in accessing transportation as a result of historical and current policy shortfalls (AFN, 2009; CCMB, 2013; Howard et al., 2014; Lavoie et al., 2016; Macdonald et al., 2015). These challenges are compounded by structural inequities, including poverty, access to housing, and food security (AFN, 2009; Black, 2009; Corvus Solutions, 2012; Lavoie et al., 2016; SE, 2012). Negative healthcare experiences have also been documented from the perspective of Indigenous patients accessing oncology care, including experiences of racism, discrimination and marginalization, all of which impact access to care (Bottorff et al., 2001; CCMB, 2013; Macdonald et al., 2015). Negative healthcare experiences, a history of oppression, and assimilationist policies within Canada contribute to a documented distrust towards healthcare providers and institutions, further marginalizing Indigenous patients from the system purportedly meant to serve them (Bottorff et al., 2001; Jensen-Ross, 2006; Maar et al., 2013; Rosicki, 2010).

At the community level, there is acknowledgement among healthcare providers that building relationships with patients is an essential aspect of delivering cancer services; racism, lack of culturally safe care, and the colonial legacy resulting in distrust of healthcare providers are barriers to accessing those services (Black, 2009; Maar et al., 2013; Wakewich et al., 2016). Building relationships with patients and families over the course of the cancer journey are key components of oncology nursing practice which require adequate time and support from leadership (Bakker et al., 2006; Davis et al., 2017). Within the context of oncology nursing practice, nurses are experiencing increasing patient acuity and workload,

increasing complexity of the healthcare system, rapidly changing landscapes of cancer treatments, and multiple competing demands impacting their ability to connect with patients and families (Bakker et al., 2006; Davis et al., 2017; Raingruber & Wolf, 2015). It is unclear whether oncology nurses, who typically do not practice within Indigenous communities, understand the importance of nurse-patient relationships on access to oncology care, or the impact of structural barriers on healthcare access.

In summary, current evidence informing our understanding of Indigenous Peoples' access to oncology care has focused on the perspectives of patients and those providing care within Indigenous communities or organizations. To date, the perspectives of oncology nurses have not been heard, which is counterintuitive given they are often the first point of contact for patients entering the oncology system and provide the bulk of clinical patient care. Although oncology nurses consider themselves as leaders in ensuring care is accessible (Oncology Nursing Society, 2020; Truant, 2018), there is little evidence regarding how oncology nurses understand structural drivers of access to care, or the contribution of patient-provider encounters in shaping access to care at the provider level. While experiences of racism and their impact on access to oncology care are documented from the perspective of Indigenous patients, the same cannot said from the perspectives of nurses who are providing care.

## Methodology

This paper presents the findings from one component of a doctoral thesis that critically examined access to oncology care among Indigenous Peoples in Canada through the perspectives and professional roles of nurses. The multiple-methods dissertation study included a national online survey conducted over a six-month period in 2019, the results of

which are presented here. The specific research objectives for the online survey were to examine: a) oncology nurses' perspectives of the barriers to accessing oncology care among Indigenous peoples, and b) how oncology nurses understand their role in improving access. Informed by postcolonial theoretical perspectives, survey development and analysis of responses drew primarily upon interpretive descriptive methods (Thorne, 2016) in addition to critical discourse analysis methods (Cheek, 2000). The research proposal and survey questions were developed in collaboration with an Indigenous healthcare provider with experience in an oncology context. Ethical approval for this study was obtained from the University of Manitoba Education & Nursing Research Ethics Board, and from CancerCare Manitoba (Appendix C).

**Theoretical Perspectives**

This study drew on postcolonial theoretical perspectives, which are rooted in analyses of power and colonial relations (Anderson et al., 2009). Research informed by postcolonial theories aims to produce transformative knowledge through the examination of the intersectional relationships between race, poverty, gender and other factors, and by explicating the impact of these factors on health and healthcare delivery (Anderson, 2002; Browne, Smye, & Varcoe, 2005). Importantly, the 'post' in postcolonial does not imply that colonialism is finished; rather, I approached this research with an assumption that "colonialism is an active and ongoing force impacting the well-being of Indigenous peoples in Canada" (de Leeuw, Lindsay, & Greenwood, 2018, p. xxiii). Such research is imperative given the extent to which colonial relations continue to shape the health and healthcare experiences of Indigenous peoples in Canada (Browne et al., 2005). Cultural safety and trauma- and violence-informed care (TVIC), which draw attention to the impact of

relationships between healthcare providers and patients on access to healthcare, were also incorporated as sensitizing frameworks. These perspectives influenced the analysis by drawing attention to the construction of structural barriers to accessing cancer care not often explicitly identified in favor of more individualistic analyses, to the ways in which power is operating at the micro and macro levels, and to patient-provider relationships and how these impact access to care.

**Sampling & Recruitment**

Canadian oncology nurses from diverse practice settings were recruited to participate in an online survey using convenience sampling strategies (Thorne, 2016). Inclusion criteria included licensure as an active practicing registered nurse and a minimum of one year of current or previous oncology nursing experience. Nurses were recruited primarily by email through third-party organizations (a national cancer nursing association and a provincial cancer center; Appendix G & Appendix H), which contained an anonymous link to the online survey. Some nurses were also recruited in-person at multiple research conferences using a printed flyer with information on how to access the survey (Appendix I). As an incentive, nurses who completed the survey could enter to win one of five $100 gift cards. An estimated 1,450 invitations to participate were extended; unfortunately, there was no ability to determine how many were received and/or read.

**Data Collection**

Using Qualtrics® online survey software, demographic information and responses to open-ended questions (qualitative) were collected anonymously; informed consent was obtained electronically (Appendix J). Following several demographic questions, a series of open-ended questions, informed by the theoretical perspectives discussed above, asked

respondents to reflect on their professional experiences with Indigenous patients (Appendix K). Open-ended questions, consistent with a qualitative research approach (Braun et al., 2020), invited respondents to share their perspectives on barriers to accessing oncology care and ways in which they, as nurses, have or could facilitate access to oncology care for this population. As part of the survey, respondents watched a digital story of one Indigenous man's experiences of accessing oncology care. This story was included to stimulate thinking about additional barriers to accessing oncology care at the systems and structural levels. Respondents were then asked to identify what barriers to accessing care they saw in that story. Survey data was exported from Qualtrics® to Excel® (demographic data) and NVIVO® (qualitative data) for analysis.

**Data Analysis**

Qualitative data from open-ended responses were analyzed inductively and iteratively, consistent with an interpretive descriptive approach (Thorne, 2016). Survey responses were read repeatedly to gain a sense of the whole. Key words, phrases, or ideas were identified in the data and used to form codes; patterns were then developed by clustering coded data into meaningful categories, which were collapsed and expanded as data analysis progressed (Thorne, 2016). NVivo® software was used during this stage to organize and sort raw and coded data. In the later stages, I moved toward a more abstract and conceptual analysis of the emergent themes as the intention was to move beyond reporting descriptive findings and articulate clinical implications and applications of the research findings. Through the conceptual analysis, postcolonial theory drew attention to broader systems of power, underlying discourses, and other structural influences on access to care. Finally, cultural

safety and TVIC frameworks guided the analysis to focus on relationships within healthcare and ways that nurses influenced access to care.

Qualitative research, particularly within the interpretive descriptive tradition, is often evaluated in terms of the credibility or quality of findings, that is, whether the analytic logic of the research can be seen, whether knowledge claims can be credibly made given the way in which the research was conducted, and whether the researcher's interpretations are trustworthy (Thorne, 2016). The credibility of the findings was enhanced by the representativeness of the participants to oncology nurses in Canada (see description below), and by the diversity of participants in terms of practice setting, professional roles, and levels of education and nursing experience. As this research was part of a dissertation, the analysis was primarily the work of the student; however, analytic insights and emerging themes were discussed with and shaped by the advisory committee, two of whom are nurses. The findings were also critically appraised by two Indigenous healthcare providers with knowledge and experience of the oncology context. Throughout the analysis, an audit trail was maintained, with analytic and interpretive decisions documented (Thorne, 2016).

## Results

### Survey Response Rate

A total of 81 responses were received from the invitation to participant in an online survey, for a response rate of approximately 6% of all invitations extended (not necessarily received, the number of which was not available). Of the 81 responses, three participants consented but did not answer any survey questions. An additional 78 participants answered some or all of the survey questions; review of these partial responses suggest that as questions required more thought and reflection, participants abandoned the survey. Finally, 34

participants completed all survey questions. Both full and partial responses were included in the analysis.

**Participants**

Survey participants were primarily registered nurses (n = 73; 94%); an additional 4 participants indicated advanced practice registration, which in Canada can include clinical nurse specialists or nurse practitioners (Table 1). These nurses had an average of 18 years of nursing experience in total, and an average of 11 years of nursing experience in an oncology setting. One quarter of nurses indicated they had a diploma in nursing (n = 19), and more than half had earned an undergraduate degree in nursing (n = 50). A small proportion of nurses indicated they had earned graduate degrees in nursing (n=9), including master's and doctoral degrees. Nurses were asked to identify their ancestry: a small proportion self-identified as Indigenous (First Nations, Métis or Inuit; n=5), most identified as non-Indigenous (n = 67), and five did not indicate their ancestry.

Nurses worked primarily in provincial cancer centers (n=60), and in-patient (hospital) settings (n=13). Some nurses worked in other cancer centers not part of a provincial cancer center (n= 6), such as community or satellite cancer centers. In addition, five nurses practiced in settings not listed, including nursing education and outpatient clinic settings. Most nurses worked directly with patients in some capacity (n=58), with a quarter working in roles more supervisory in nature including clinical resource, educator, charge, and management roles (n=20). When asked how frequently they worked with Indigenous patients, the majority indicated either at least daily (n=15) or weekly (n=35).

**Table 1**

*Characteristics of Survey Respondents*

*Participants could indicate more than one practice setting

| | **All Participants (n=78)** | **Partial Completions (n=44)** | **Full Completions (n=34)** |
|---|---|---|---|
| **Nursing Experience** | | | |
| Average # Years Nursing | 18 | 19 | 17 |
| Average # Years Oncology Nursing | 11 | 11 | 11 |
| | **# of responses (%)** | **# of responses (%)** | **# of responses (%)** |
| **Type of Nursing Registration** | | | |
| RN | 73 (94%) | 42 (95.5%) | 31 (91%) |
| APN | 4 (5%) | 2 (4.5%) | 2 (6%) |
| Not specified | 1 (1%) | 0 | 1 (3%) |
| **Highest Level of Professional Education** | | | |
| Diploma | 19 (24.5%) | 13 (30%) | 6 (18%) |
| Undergraduate Degree (i.e., BScN, BN) | 50 (64%) | 27 (61%) | 23 (67.5%) |
| Graduate Degree (i.e., MN, MSc, PhD) | 9 (11.5%) | 4 (9%) | 5 (14.5%) |
| **Type of Oncology Practice Setting*** | | | |
| Provincial Cancer Center | 60 (71.5%) | 34 (74%) | 26 (66.5%) |
| Satellite Cancer Center | 6 (7%) | 4 (9%) | 3 (7.5%) |
| In-patient Setting | 13 (15.5%) | 6 (13%) | 7 (18.5%) |
| Other | 5 (6%) | 2 (4%) | 3 (7.5%) |
| **Type of Nursing Position** | | | |
| Direct patient care | 58 (74%) | 32 (73%) | 26 (76.5%) |
| Non-direct patient care (clinical resource, charge, manager) | 20 (26%) | 12 (27%) | 8 (23.5%) |
| **Frequency of working with Indigenous patients** | | | |
| Daily (at least once per day) | 15 (19%) | 8 (18%) | 7 (21%) |
| Weekly (at least once per week) | 35 (45%) | 23 (52%) | 12 (35%) |
| Monthly (at least once per month) | 13 (17%) | 7 (16%) | 6 (18%) |
| Occasionally (at least once per year) | 15 (19%) | 6 (14%) | 9 (26%) |
| **Ancestry** | | | |
| Self-identify as Indigenous (First Nations, Métis, Inuit) | 5 (6.5%) | 3 (7%) | 2 (6%) |
| Self-identify as other than Indigenous | 68 (87%) | 36 (82%) | 32 (94%) |
| Not specified | 5 (6.5%) | 5 (11%) | 0 |

To demonstrate representativeness of the sample of oncology nurses, the membership statistics of the Canadian Association of Nurses in Oncology [CANO] were consulted. There

were 1,137 members of CANO in 2019, which represent a large portion of oncology nurses in Canada (Canadian Association of Nurses in Oncology, 2019). More than two thirds of CANO members are educated at the undergraduate level, approximately one quarter at the diploma level, and less than a quarter at the graduate level. The majority of CANO members practice in direct patient care roles. Given the similar demographic trends, those who responded to the survey do not represent a skewed sample concerning education level and type of nursing practice among oncology nurses in Canada. However, these descriptive statistics do not speak to their knowledge of healthcare and Indigenous Peoples in general, and of colonial histories and current day structures in particular.

## Survey Results

Analysis of survey responses began with categorizing the types of barriers to accessing oncology care identified by nurses. I was interested in how nurses discussed these barriers – as individual, systems or structural level barriers – as these narratives shed light on how nurses understand access to care, and therefore, how they might address barriers. When considering their role, nurses primarily saw themselves as *mediators* of access to oncology care, which at times was constrained by a biomedical model of nursing practice.

### *Nurses' Narratives of Barriers to Accessing Oncology Care*

Nurses discussed multiple barriers to accessing oncology care for Indigenous Peoples and their narratives primarily focused on the actions or domains of individual patients or healthcare providers. Although some nurses talked about healthcare system barriers, few connected the individual and systems level barriers to societal structures underlying these barriers that result in inequitable access to oncology care for Indigenous Peoples.

**Individual.** The barriers most commonly discussed by nurses included transportation, communication, financial, and psychosocial challenges. Nurses tended to construct these as barriers to accessing oncology care at the individual level, for example, speaking about barriers as "sometimes non-compliance; sometimes comprehension on anti-nausea meds, central lines; sometimes no shows on appointments" (S24), without fully acknowledging contextual factors shaping or creating these barriers.

Nurses described transportation as "more often than not a barrier" (S21) to accessing oncology care (see also S26, S40, S61). Given the geographical location of many Indigenous communities and the lack of services available locally, many Indigenous patients must travel to larger urban centers to access care. At times, nurses' observations regarding transportation barriers took a paternalistic tone. For example, one nurse stated, "sometimes…patients are not aware that some appointments are time sensitive or should not be delayed" (S78), while another nurse highlighted a patient's "inability to attend appointments reliably" (S35). These narratives locate the 'problem' of transportation with the individual and their lack of 'awareness' rather than contextual factors beyond the individual that may be at play.

Nurses described communication as a barrier to accessing oncology care (S45, S52). Nurses often rely on telephone access to monitor side effects of treatment and assess patient concerns, however, within the context of financial challenges and unreliable telecommunication services in some Indigenous communities, patients may not have consistent access to a telephone (for examples, S21, S51). Nurses also identified language as a barrier to effective communication (S13, S22, S46, S70), and described frustration at their ability to conduct patient teaching when patients were not able to communicate in English (S55). Patient education presents real challenges within the context of oncology care, where

treatments are complex, side effects may be significant, care is primarily provided on an outpatient basis and time is limited. Through a postcolonial lens, it is likely that telephone access and language intersect with cultural differences, unequal relations of power, and the historical context of Indigenous patients, adding additional layers of complexity to communication challenges, which nurses in this study did not discuss.

Poverty and financial ability to afford expenses not covered under health insurance were highlighted by nurses as barriers (S35, S72); mental health issues and homelessness also impacted some patients' ability to attend appointments and complete treatment:

> The patient was dealing with homelessness, chemical addictions, and had recently moved from a remote community to the city…this patient was not always reliable to show up for appointments (S35).

Lack of psychosocial supports, particularly among patients who relocated to urban centers for cancer treatment, meant some patients had to navigate the cancer treatment experience alone, resulting in tangible consequences, such as missed appointments or medications (S41, S75).

A small proportion of nurses highlighted how interactions between patients and healthcare providers can constitute barriers to accessing oncology care. Nurses described how a lack of understanding of cultural values among healthcare providers was problematic at times (S13, S40). One nurse explained:

> The healthcare team really struggled to honor this patient and her family's time schedule, as it was quite different than how they conceptualized their time schedule…Often, this would result in frustration for the patient, the family, and the healthcare team. The barrier that this patient and family faced was a lack of education

> for healthcare staff about navigating the complex care needs of Indigenous people (S40).

Nurses recalled negative healthcare experiences of Indigenous patients, such as those whose health concerns were repeatedly dismissed by healthcare providers who did not take them seriously or assumed that reported symptoms were psychological rather than physical (S23, S70). Some nurses recognized these experiences as a barrier to accessing care, particularly in response to the digital story highlighting one patient's oncology care experiences; in several cases this was explicitly labelled as racism (for example, S56, S80), whereas other nurses used the terms discrimination or stereotyping that 'could be' interpreted as racism (S03, S38). A few nurses indicated that the dismissal of patient concerns and experiences of racism impacted access to timely and high-quality care. One nurse relayed a particularly upsetting experience:

> The patient…had been mis-diagnosed until his cancer presented as stage 4, and he was in constant pain. He had trouble numerous times with his pharmacy, as they didn't want to dispense his pain meds because they felt that the dose prescribed was inappropriate and that he must be drug-seeking. He was tearful and said 'I wish I was white. Then I wouldn't have to be in pain'. His suffering was directly related to incorrect assumptions and racism (S23).

Although there was some understanding of discrimination and racism as impacting access to care, this was uncommon and more often absent in the survey responses. Moreover, although through a critical perspective, racism is understood as rooted in historical, political and social structures, nurses in this study tended to convey an understanding of racism at the interpersonal level.

**Systems.** Nurses highlighted the complex and siloed nature of the Canadian healthcare system and challenges navigating this system as significant barriers to accessing oncology care. Nurses indicated that difficulty accessing *primary care* – essential to gaining entry into the oncology system – can be a problem for some Indigenous patients, resulting in limited cancer screening opportunities and delays in cancer diagnoses (for example, S03, S51, S56). However, several nurses perceived that while some Indigenous patients have challenges accessing primary care, once they are in the oncology system, there are no barriers to accessing oncology care: "after arriving at our hospital there were no barriers to treatment as every patient is categorized and assigned to a protocol that best treats their disease" (S18; see also S03, S08). Limited local availability of other health professionals (such as dieticians or speech-language pathologists) and specific services such as diagnostics were also noted to impact the quality and timeliness of care (S14, S21, S35).

**Structural.** Structural barriers to accessing healthcare are those that are embedded in the historical, economic, social and political fabric of a society. A few nurses identified social factors, including financial challenges, unemployment, homelessness, and lack of housing as barriers to accessing oncology care, however few other structural barriers were identified (S21, S35, S55). Notably, although these factors are rooted in structures, they were most often framed as individual challenges. Although nurses did not discuss policies as barriers to access, several nurses emphasized the role nurses can play in advocating for policy change at all levels of government.

### *Nurses Roles as Mediators of Access to Care*

Most nurses saw themselves as active participants in the process of helping patients gain access to oncology care, working on behalf of patients to bridge the gaps in care. As

intermediaries in access to care, nurses functioned as coordinators, navigators, advocates and educators. Survey responses indicating that nurses see themselves as able to influence access to care suggest that nurses have, on some level, an implicit understanding of their currency or power within the healthcare system to act on behalf of their patients.

Nurses served as mediators of access to care by coordinating care on behalf of patients to ensure seamless delivery of care (S09, S25, S30, S40). Some nurses communicated that they were the 'glue' that held the multi-disciplinary team together, and an essential liaison between community and oncology care settings (S18, S25, S40, S75). Care coordination at times required significant investments of time and effort:

> I was able to help him apply for Seniors Benefits to help pay for his meds and supplements. I was able to get social work involved. I was able to arrange for his wife to be in contact with a speech-language pathologist when they returned to their community. I had to arrange for his diet supplements to be shipped to his community via bus (S14).

Nurses also guided patients in navigating the oncology system by troubleshooting barriers and connecting them to resources (S03, S04, S35, S50, S72). To aid in navigating the system, some nurses emphasized the need to "increase [our] own awareness of patients' contexts and healthcare services available in their community" (S75; see also S30, S77). Although nursing roles specific to patient navigation (including nurse navigators and Indigenous navigators) exist within most oncology settings in Canada, and many nurses discussed referring patients to a navigator, some nurses saw that supporting the patient to navigate the healthcare system was also part of their role (S02, S14, S18, S21, S30). One nurse described their role as "doing as much 'leg work' as I can. Providing any names, numbers, services etc." (S35).

Common among many responses was the perspective that nurses play a role in "advocating for families and patients when they may not speak up for themselves" (S25). As advocates, nurses occupy a middle position between patients and healthcare providers, institutions, systems and governments. Some nurses highlighted specific ways in which they could advocate for individual patients, such as timely cancer diagnosis or effective pain control (S03, S18, S23, S38) while other nurses discussed the bigger role that they could play as advocates (S23, S80). One nurse explained: "Nurses are ideally suited to ensure people have access to oncology care. As a profession, we have not always been encouraged to use our voice, particularly when it comes to political issues. However…nurses are well positioned to influence policy and improve care" (S56). Similarly, nurses function as intermediaries through their roles as educators, ensuring patients and families understand their diagnosis, treatment, and potential side effects (S14, S39, S41). Although most nurses discussed the importance of education out of concern that patients understand when and where to access care if needed (S26, S40, S56, S67), some took a more paternalistic approach (S35, S70). For example, one nurse noted how patients "need to be informed in their own health care" (S12). These narratives construct a binary of 'us/them' and tend to be used as a strategy to place responsibility for accessing care solely on the patient.

Developing relationships with patients was an important way for nurses to improve access to oncology care for Indigenous patients (S13, S42, S52, S56). A relational approach to care recognizes that needs extend beyond the physical, and that relationships within healthcare settings are an important component of nursing care. Although some form of nurse-patient relationship is implicitly needed for nurses to function as mediators of access as described above, some nurses discussed this more explicitly:

> I think that relationship is important in caring for people who have barriers to access. Nurses are well poised to develop relationships with patients…relationships can provide a safe place in which to share concerns or other issues (S75).

Relationships are particularly important given the context of colonizing relationships within Canada between Indigenous Peoples and institutions, and the resulting distrust that exists among Indigenous Peoples towards healthcare institutions. Several nurses expressed the need to increase education on Indigenous history in nursing curriculums, with the recognition that understanding this history is one essential component of providing culturally safe care (S13, S75). Endeavouring to be sensitive to the patient's history, avoiding judgment, and making the patient feel safe were identified as ways to improve access to care (S35, S45, S69). As a result of developing trusting relationships, nurses could better understand and meet the needs of patients.

However, this perspective was not expressed by all nurses: "at the individual level, I can…help our patients feel safe in the system - however, making their experience better does not necessarily improve their access" (S14). Indeed, while many nurses saw themselves as mediators of access to oncology care, some nurses did not talk about themselves as having a role in mediating access to care. These nurses tended to identify *other* healthcare professionals (such as nurse navigators) or services (Indigenous-specific services) as responsible for addressing any gaps in care or barriers to accessing oncology care (S22, S29, S61, S73, S76). Notably, those who did not see themselves as playing a role in facilitating access to oncology care worked less often with Indigenous patients and had fewer total years of nursing experience, which suggests they may not have a good understanding of the barriers Indigenous patients face.

**Biomedical Constraints and Nursing Practice.** Although many nurses saw themselves as playing a role in improving access to oncology care, they also felt constrained in their abilities to practice in ways known to improve access to care. To illustrate a common response among survey participants, this nurse expressed frustration at the lack of time for nursing care beyond patients' physical needs:

> There isn't enough time in a busy tertiary cancer centre (which is over capacity) to get into detail about all the important aspects of our patients. It also takes trust to develop relationships, and this also takes time (S003).

Nurses also acknowledged that their lack of understanding of services needed or available for Indigenous patients with cancer (S002, S022, S035, S041, S074, S080), barriers faced (S024), and Indigenous history and perspectives on health (S042, S067, S075) impacts their ability to improve access to oncology care. Several nurses perceived a lack of power to make positive changes within a hierarchical healthcare system (S023, S045, S075). These concerns highlight how nursing practice is subject to the powerful influences of the biomedical and business models, both structural barriers to healthcare access.

## Discussion

Exploring oncology nurses' perceptions of access to oncology care provides an opportunity to consider where their attention is focused within their practice and experiences caring for Indigenous Peoples. Many barriers to accessing oncology care identified in this study are similar to those previously identified, which include: difficulties accessing primary and oncology care locally, difficulties accessing or arranging transportation and accommodations, language and lack of interpretation services, inadequate financial resources and lack of support for patients who relocate for cancer treatment (Black, 2009; CCMB, 2013;

Corvus Solutions, 2012; Hammond et al., 2017; Howard et al., 2014; Lavoie et al., 2016; MacDonald et al., 2015; Olson et al., 2014; SE, 2012). Notable discourses operating within the nurses' responses included a narrative of individualism resulting in limited insight into structural contexts shaping access to care, and the absence of acknowledging racism as a barrier to accessing care. While some nurses spoke about the importance of relationships and trust-building, the key roles oncology nurses saw themselves playing to improve access to care were through care coordination, education, advocacy and relationship-based care with individual patients. However, nurses also talked about the hegemonic model of biomedicine that dominates Western healthcare contexts, which constrained their ability to practice in ways that maximize access to care and provide high-quality care.

The diverse barriers identified by nurses are reflections of barriers well documented to be shaping Indigenous Peoples experiences with accessing oncology care. This study advances the knowledge about how these barriers are understood among oncology nurses and therefore, most likely to be addressed. Findings suggest that oncology nurses construct barriers to accessing care primarily as barriers at the individual and systems levels. In some ways this is not surprising and reflects the strong commitment to individualism within Western societies, along with the dominance of biomedicine in healthcare and on nursing as a discipline. Individualism holds that humans are unique and can be abstracted from their context, with success and failure a result of individual character rather than social structures (DiAngelo, 2018). The biomedical model and its focus on the individual are woven into the fabric of nursing within Western contexts, extensively shaping nursing theory and knowledge development (Browne, 2001; Hartrick Doane & Varcoe, 2015; Hilario et al., 2018), and within this frame, nurses tend to know and speak about access to care as an individual

responsibility. In the current study, this was reflected through nurses' statements that "non-compliance", "no shows for appointments" and ability to afford medications were barriers to accessing oncology care. While these may be important issues to address, there are significant structural inequities shaping a patient's ability to 'comply' with treatment, 'show up' for appointments, or 'afford medications' that were not spoken about in the survey responses. However well-meaning, nursing practice focused on the individual will fail to adequately address broader issues of marginalization, social inequities and structural determinants of health and risks further entrenching patterns of inequitable access to care (Browne, 2001; Raphael et al., 2008).

The influence of biomedicine was also evident in nurses' complaints regarding a lack of time to develop trusting relationships, provide teaching and supportive care, and address the broader context of patients' health. These concerns point to a system that prioritizes time- and cost-efficiency over high quality nursing care. The stated limited understanding among nurses about Indigenous ways of knowing, histories of colonization, and health care needs ought to be interpreted within the context of a powerful biomedical model that pushes nursing education and practice towards assessing and addressing physiological needs abstract from broader social and historical contexts. The fragmented nature of the current healthcare system also highlights the biomedical propensity to treat bodily parts and diseases as dis-integrated and separated from the whole person. Thus, the biomedical and business models, and the ways in which healthcare is structured as a result, become significant barriers to accessing care. Although these systemic and structural barriers were not always visible to nurses, their influence was felt.

The demonstrated lack of awareness regarding structural influences on access to oncology care is concerning, and yet consistent with results from a recently published scoping review (Horrill et al., 2019; Chapter 2). Many nurses in this study recognized their ability to practice in ways that improve access to oncology care for Indigenous Peoples, and these were primarily strategies to improve care for an individual patient rather than strategies to address systems or structures. Although the structural nature of some of the barriers to accessing oncology care was implied, it seemed as though nurses lacked the language needed to discuss these barriers as structural rather than individual. Alternatively, nurses' social position, particularly among those who are white, allows them to remain oblivious to structures of inequity (Allen, 2006; Hall & Fields, 2013; McGibbon et al., 2014).

This is not entirely surprising given that although a *social* determinants of health framework has been increasingly embraced over the last several decades, a focus on *structural* determinants of health and healthcare access has not been sustained in clinical practice (McGibbon et al., 2014). Moreover, a structural determinants of health framework is rarely incorporated into nursing education (McGibbon et al., 2014; van Herk et al., 2011), and until recently, concepts such as cultural safety, which facilitate reflection on social positioning and structural inequity, have not been included in nursing curricula or standards of practice in Canada (Baba, 2013). Understanding how health and healthcare are situated in social, political and historical structures is critical for nurses to improve the quality of care and access to care (Beavis et al., 2015; McGibbon et al., 2014). Structural competency education has been proposed as one strategy to improve the ability of clinicians to see the clinical and patient impacts of 'upstream' or structural determinants of health (Metzl & Hansen, 2014). Incorporating education on structural determinants of health into nursing curricula and

continuing education is imperative to ensure nurses are adept in recognizing, understanding and discussing structural influences on access to care, which could open space for nurses to consider how they could address these determinants of health.

One finding of particular interest was the notable absence of racism found within nurses' narratives of access to oncology care. Despite extensive evidence over the last several decades that Indigenous Peoples experience racism and discrimination in healthcare encounters that seriously compromises access to care, nurses' discussions of barriers to accessing care rarely included racism. Narratives tended to focus on barriers at the individual patient level, with very little acknowledgement of how systemic racism impacts access to care. Moreover, even when explicitly named and described within the digital story (as part of the survey), only 11 nurses identified racism as a barrier to accessing care. van Herk and colleagues (2011) argue that racism is not often considered an important issue within nursing, and issues of racism, power and oppression have historically not been taught within professional nursing education. Thus, it is possible oncology nurses lack understanding or awareness of how racism operates within healthcare settings and its impact on access to care. The absence of racism as a key finding does not necessarily represent the perspectives of *all* nurses who participated in this study, nor that nurses are *intentionally* avoiding racism, and indeed some nurses did identify racism (both interpersonal and structural) as problematic within healthcare settings. However, the absence or silence around racism within healthcare settings is not unknown, and in an effort to understand why that might be, I offer three discourses that operate to sustain the invisibility of racism: political correctness, egalitarianism, and the good/bad binary (Table 2).

**Table 2**

*Discourses Sustaining the Invisibility of Racism*

| Discourse | Description | Example | Effect |
|---|---|---|---|
| **Political Correctness** | Avoiding discussing or naming racism because it is politically incorrect (Henry & Tator, 2006; Hilario et al., 2018) or socially taboo (Tang & Browne, 2008) | Reluctance/hesitancy/discomfort in naming racism as a barrier; using hedging language: "Provider bias, *maybe* even prejudice/racism on behalf of the primary care physician" [emphasis added] (S003). | Ignores or downplays the prevalence of racism within healthcare settings |
| **Egalitarianism** | Purporting to treat all patients the same (Browne, 2005, 2007; Tang & Browne, 2008)<br><br>Implying that if all patients are treated equally, they must be treated fairly (Henry & Tator, 2006)<br><br>Presenting healthcare institutions as "discrimination-free" (Tang & Browne, 2008) | "I treat patients with an Indigenous background daily…these particular patients are treated the same as every patient within [cancer center]. They are given the most up to date options for their cancer treatment and treated with care and compassion" (S039) | Denies existence of racism at the individual and structural levels within healthcare contexts – 'we cannot be racist because we treat everyone the same' |
| **Good/Bad Binary (DiAngelo, 2018)** | Understanding racism as specific 'acts' committed by 'bad' people, rather than as *systematically* and *structurally* produced; denying the possibility that 'good' people can participate in racism (DiAngelo, 2018)<br><br>Racism within healthcare settings becomes an example of unprofessional behavior rather than an expression of ideologies embedded within social structures (Hilario et al., 2018) | Identifying behaviours or specific interactions between *other* healthcare providers and patients as racism (racism is a problem among healthcare providers in nursing stations or emergency rooms)<br><br>Little acknowledgement of how these acts are situated within and produced by comprehensive systems of racism | Obscures the ways in which it operates through systems and structures to shape access to oncology care |

Finally, although many nurses expressed an understanding of their roles as individual nurses and of the role of nursing as a profession in improving access to oncology care, notably, a small proportion of nurses did not see themselves as playing a role in access. This viewpoint may be influenced by an understanding of healthcare access as premised on geographical location and availability of services, and a view that nurses have little impact on these broader systemic factors. Alternatively, this view suggests a poor understanding of the impact of trusting patient-provider relationships, free of racism, discrimination or other negative experiences, on access to healthcare and oncology care. Incorporating principles of cultural safety and trauma/violence-informed care into education and practice would highlight the importance of relationships on access to care and draw attention to the contextual factors shaping access to care, including social and structural determinants of health (Horrill et al., 2020b; Chapter 3). Cultural safety has been noted to be a key element of providing high quality, accessible healthcare for Indigenous Peoples (Browne et al., 2016; Health Council of Canada, 2012; Horrill et al., 2020b). Cultural safety will require us as nurses to engage in reflexive processes and get uncomfortable with our own biases and attitudes, our shared history of colonialism in Canada, and how we may have been unaware of or complicit in perpetuating structural inequities (Papps, 2015). Cultural safety, with its focus on unequal relations of power and patient-provider interactions, will help us as nurses to develop an awareness of how racism is operating within healthcare settings, at both the individual and structural levels to shape access to healthcare. However, although cultural safety is enacted within the individual relationships between nurses and patients, the ultimate goal is a change in our collective relationships (Greenwood et al., 2017). As such, cultural safety approaches

must be instituted systematically and supported by structures and processes (Brooks-Cleator et al., 2018; Browne et al., 2015; Wylie & McConkey, 2019).

### Strengths & Limitations

The findings from this study should be considered in the context of several strengths and limitations. The total sample size (n=78) was consistent with medium-sized qualitative survey studies (Braun et al., 2020). The online survey format allowed us to access a geographically dispersed sample of oncology nurses, and elicit a wide range of perspectives, a particular and unique strength of using online surveys as qualitative data collection tools (Braun et al., 2020). Although common in surveys of nurses, with time, workload and perceived value or relevance of the topic cited as barriers to participation (VanGeest & Johnson, 2011), a low response rate to the email invitations to participate was noted. However, as discussed above, there were overall similarities between participants in this study and those who are members of CANO, which suggests that the sample holds some measure of representativeness. Findings may have been influenced by attrition bias, as less than half (34 of 78) of study participants fully completed the survey, however the characteristics of partial survey completers and full survey completers were similar. Attrition may have been related to the nature of the questions, with open-ended questions requiring more time and effort to answer (Dillman, Smyth, & Christian, 2009), and resulting in higher rates of item non-response (Miller & Lambert, 2014).

## Conclusion

This examination of nurses' perspectives of access to oncology care for Indigenous Peoples demonstrates how narratives of individualism are embedded within nursing practice and shape how nurses understand and address access to care, while structural barriers to

accessing oncology care, including racism, remain relatively invisible. I reiterate that nurses are not intentionally ignoring structural inequities, but rather are taking up broader social discourses that focus their attention at the individual level and work to sustain the invisibility of racism within healthcare settings. However, continually privileging an understanding of equitable healthcare access centered on individual patients risks entrenching these inequities. To begin to rewrite nurses' narratives, nurses must "cast their gaze toward the conditions that perpetuate inequalities" (Cameron et al., 2014, p. E14). Embedding a structural understanding of health and healthcare access into nursing education and practice will open space to move toward redressing inequitable access to oncology care for Indigenous Peoples.

By critically examining nurses' narratives on access to oncology care, we can begin to provide oncology nurses with tools to improve access to care for Indigenous peoples, and better support them in delivering high quality care. Through their interactions with patients and attention to structural determinants of health, nurses have the power to contribute to safe healthcare spaces and address inequities in access to oncology care for Indigenous Peoples in Canada.

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## Chapter 5: Preamble

Chapter 5 presents the results of the second of two primary research studies. In this study, I recruited oncology nurses, many of whom participated in the online survey, to complete in depth interviews. The purpose of this study was to gain a deeper understanding of the perspectives of oncology nurses on access to oncology care for Indigenous Peoples, and to better understand their work in delivering care to this population. I was especially interested in the discourses shaping access to care, but also how discourses were impacting oncology nurses and their practice. The findings add to the evidence regarding challenges in access to oncology care among Indigenous Peoples, but also shine a light on the challenges faced by oncology nurses in their practice. In particular, the findings begin to illuminate the structural constraints shaping the work of oncology nurses which impact their ability to influence access to oncology care.

### Author Contributions

I conceptualized and designed the study, under the supervision of my advisors. I conducted the data collection and analysis and wrote and revised the manuscript in consultation with Dr. Schultz. Drs. Schultz, Martin and Lavoie provided critical feedback throughout the development of the manuscript, which will be submitted for publication upon completion of the thesis.

## Abstract

Within Canada, substantial evidence documents Indigenous Peoples' experiences of racism, discrimination, and judgment within the healthcare system, all of which deter and delay their access to healthcare services. Given this, a significant barrier to accessing healthcare is rooted in the practices of healthcare providers. As inequitable healthcare access often underlies explanations of health disparities, access challenges within the context of oncology care are likely influencing the growing cancer disparities among Indigenous Peoples in Canada. Yet the perspectives of healthcare professionals who provide oncology care have yet to be explored. This study examined Canadian oncology nurses' understandings of access to and the delivery of oncology care for Indigenous Peoples, and the contextual elements shaping nursing practice and access to care. Informed by critical and postcolonial theoretical perspectives, a multiple methods design was used, which included semi-structured interviews with 15 oncology nurses. Interpretive descriptive and critical discourse analysis methods guided the study design and analysis of data. Findings reveal that nurses see the healthcare system as broken and described barriers to accessing oncology care that are layered and compounding. Lack of culturally safe care was articulated as a significant issue preventing equitable access to oncology care; however, study findings also challenge popular discourses in Canada that all healthcare contexts are culturally unsafe, as the narratives of nurses demonstrated their pursuit of cultural safety and trauma-and violence-informed care in oncology settings. Yet biomedical discourses were pervasive, and suppressed discourses of cultural safety and trauma-and violence-informed care. Nurses' endeavours in relational practice were undermined, unsupported and superseded by the dominant biomedical discourses that promoted the 'business' of healthcare and discounted the relational work of

nurses. Research is needed to better understand the impact of cultural safety and trauma-and violence-informed care frameworks on healthcare access, and the mechanisms needed to support such frameworks in nursing practice.

**Access Denied: Nurses' Perspectives of Access to Oncology Care among Indigenous Peoples in Canada**

Inequitable access to healthcare services is well-documented among Indigenous Peoples in Canada, and of the various barriers reported are negative healthcare experiences and poor treatment at the hands of healthcare providers (Allan & Smylie, 2015). Indigenous Peoples commonly face racism, discrimination, and judgment when accessing healthcare services, which leads to delays or avoidance in accessing healthcare services, or expectations of mistreatment by healthcare providers (Browne & Fiske, 2001; Browne et al., 2011; Cameron et al., 2014; Goodman et al., 2017; Kitching et al., 2020; Monchalin et al., 2020; Nelson & Wilson, 2018; Wylie & McConkey, 2019). In particular, reported inequities in access to oncology care (care related to a potential or actual cancer diagnosis) among Indigenous People in Canada are articulated as one potential factor underlying growing cancer disparities among Indigenous Peoples in Canada, which include later cancer stage at diagnosis and poorer survival (Horrill et al., 2019a; McGahan et al., 2017; Nishri et al., 2015; Sheppard et al., 2010; Withrow et al., 2017). Accessing care for the diagnosis or treatment of cancer means navigating a hostile system in the midst of a personally vulnerable and challenging time, which may include feelings of overwhelm, shock and helplessness (Loppie & Wien, 2005). Indigenous patients experience additional barriers to accessing oncology care at the individual, systems and structural levels which intersect with negative healthcare experiences, such as racism and discrimination, to further entrench access inequities (Horrill et al., 2019b). Yet despite substantial evidence documenting factors that impact access to oncology care, and the known impacts of Indigenous Peoples' negative healthcare experiences on access to care, there is limited research exploring the perspectives of healthcare professionals who provide

oncology care. Moreover, as the largest body of healthcare providers within Canada, nurses' everyday practice sits at the nexus of intimate personal lives of patients and broader health and social structures. As such, nurses bring important perspectives on the challenges faced by Indigenous Peoples in accessing oncology care, their work in addressing gaps in care, and the context in which they strive to address inequitable access to care. In this paper, I report the findings from a study exploring nurses' perspectives on access to and the delivery of oncology care to Indigenous Peoples in Canada.

**The Context of Oncology Nursing Practice**

Oncology nurses play a key role in the delivery of care along the cancer continuum, including care related to cancer prevention and screening, early detection, diagnosis and treatment of cancer, symptom management and supportive care, education, rehabilitation, long-term follow-up and palliative care (Young et al., 2020). The majority of oncology nurses in Canada work in direct patient care roles and deliver highly specialized clinical care (Canadian Association of Nurses in Oncology [CANO], 2001, 2019). Oncology nurses work collaboratively within interdisciplinary teams and play significant roles in coordinating care across the continuum and assisting patients in navigating the healthcare system (Lemonde & Payman, 2015; CANO, 2001). The increasing acuity of patients and expanding complexity of nursing care in recent years requires oncology nurses to have specialized knowledge and skills (Bakker et al., 2006; Lemonde & Payman, 2015). Coupled with rapidly evolving clinical care, healthcare restructuring within Canada over the past several decades has resulted in significant changes to oncology nursing practice, including increasing workload and insufficient staffing levels, challenges in facilitating professional development among oncology nurses, lack of support for innovative practice changes, and decreasing quality of

nursing care (Bakker et al., 2006, 2010, 2012; Lemonde & Payman, 2015). A shift towards a corporate model of healthcare has meant a loss of clinical nursing leadership, and fewer opportunities for nurses to engage in policy decisions or make organizational change (Bakker et al., 2010; Varcoe & Rodney, 2009). Beyond the impacts of restructuring and corporatization, healthcare contexts and the work of oncology nurses are also organized through discourses.

## Discourses Influencing Nursing Practice

Discourses, or ways of thinking and speaking, provide a common (though often unseen and unspoken) set of assumptions that constitute reality in specific ways (Cheek, 2000; Mills, 1997). Within the healthcare context, multiple discourses operate at any one time to structure healthcare systems and clinical practice: "they determine who can speak, when, and with what authority, and conversely, who cannot" (Cheek, 2000, p. 23). Although invisible, these discourses, or "wider social relations" have profound impacts on nursing practice and patient-provider relationships (Browne, 2007, p. 2165). Here I highlight some of the discourses operating within the Canadian healthcare context broadly, and within nursing specifically, that are relevant to this study.

### *Social Justice Discourses*

Social justice has been described as a core disciplinary value within nursing (Thorne, 2014), and "central to nursing's mission" (Meleis & Glickman, 2014, p. 309). Social justice discourses have increased over the past fifteen years within the professional bodies of both nursing and medicine (Browne & Reimer-Kirkham, 2014). Promoting justice is identified as a core ethical responsibility of nurses in Canada (Canadian Nurses Association, 2017) and has increasingly been a focus within professional nursing bodies (eg., Canadian Nurses

Association, 2010). Yet Browne and Reimer-Kirkham (2014) argue that nurses do not have a solid grounding in what social justice looks like at the point of care; the gap between social justice discourses in nursing and socially just actions by nurses is underpinned by ideologies of race and the 'other' (Anderson et al., 2009). This gap is further complicated by the increasingly corporatized context of healthcare, which suggests the need for an examination of not only the inability of nurses to enact social justice at the point of care, but also the conditions of nurses' work that might make this so (Browne & Reimer-Kirkham, 2014).

### *Discourses about Cultural Safety and Indigenous Peoples*

Among nurses, assumptions of Indigenous Peoples as 'drug-seeking', dependent on 'the system', or as prone to alcohol or narcotic abuse are well documented (Browne, 2005, 2007; Goodman et al., 2017; Monchalin et al., 2020; Phillips-Beck et al., 2020; Tang & Browne, 2008). These assumptions tend to reflect wider social discourses in Canada that position Indigenous Peoples as 'other' (Browne, 2007). Culturalist and racializing discourses, also common in nursing, attribute health and social problems to presumed 'cultural' differences or racial characteristics (Browne, 2005). 'Culture' or 'race', then, are used as the primary explanation for poor health among Indigenous Peoples rather than the social, political, economic and historical systems that create and sustain the conditions for health (Browne, 2005). While nurses do not necessarily intentionally take up these discourses, such discourses are embedded within nurses work and become a lens through which nurses view and interact with patients (Browne, 2005; Tarlier et al., 2007).

Cultural safety, a concept developed within the New Zealand nursing context in the 1980s and 1990s, has been proposed as one framework to address the racializing and culturalist discourses and the persistent health and social inequities among Indigenous

Peoples (Papps & Ramsden, 1996). Since that time, there has been significant interest in cultural safety within nursing and other healthcare professions in Canada (Guerra & Kurtz, 2017). Over the past several decades, discourses within nursing have shifted from theoretical explorations of cultural safety (see for example Anderson et al., 2003; Reimer Kirkham et al., 2002) to application and evaluation (see for example Brooks-Cleator et al., 2018; Browne et al., 2016). Moreover, given the Truth and Reconciliation Commission of Canada's recommendation that skills-based training in cultural safety and anti-racism be required in nursing education, cultural safety training is increasingly a requirement for accreditation of schools of nursing within Canada (Kurtz et al., 2018). Yet there remains a fundamental disconnect between competencies embedded in educational frameworks and the realities of clinical practice within healthcare institutions, where experiences of culturally unsafe and racist treatment by healthcare providers towards Indigenous Peoples are reported regularly by the media (Bernhardt, 2020; Kirkup, 2020).

***Biomedical Discourses***

While social justice and cultural safety discourses position nurses as agents of change, at the same time, nurses are situated in environments dominated by biomedical discourses and within a healthcare hierarchy typically controlled by physicians (Canam, 2008; Cheek, 2000; Coombs, 2004). Characterized by a strong commitment to objectivity, efficiency, and technical care, biomedical discourses are the bedrock of healthcare in Canada (Raphael & Curry-Stevens, 2016). The discourse of 'efficiency', as the holy grail of healthcare reform, has gained cult-like status in recent decades (Stein, 2002) with its emphasis on reducing length of hospital stays, streamlining processes and minimizing healthcare costs (Blanchet Garneau et al., 2019). Concerns regarding quality of care have diminished in favor of gains in

'efficiency', which seems to be primarily understood as "providing physiological care and medical treatment as quickly and cheaply as possible" (Varcoe & Rodney, 2009, p. 129). Emphasizing the provision of technical care as the highest (and sometimes only) priority has devalued the relational work of nurses, including their work in care coordination and education, and their ability to address the psychosocial and structural needs of patients (Canam, 2008; Varcoe & Rodney, 2009).

Discourses of individualism are also well embedded within biomedicine, where individual actions are seen as the primary source of health and illness, while the sociopolitical and historical determinants of health and healthcare access are dismissed (Browne, 2001; Horrill et al., 2018; Raphael & Curry-Stevens, 2016). Goals of healthcare, then, include physiological diagnosis, treatment of individual body parts, and cure of illness. Within this context, 'patient compliance' has received significant attention, with the assumption that not only do patients share these goals (diagnosis, treatment and cure), but that compliance with physician or nurse orders is both in patients' best interests and should be fostered (Cheek, 2000; Hallett et al., 2000). Hess (1996) documents healthcare providers' near obsession with patient compliance. Such discourses are deeply ingrained in nursing practice and are particularly evident through the widespread use of terms such as 'nonadherence' and 'noncompliance' by nurses (Hall, 1999; Hallett et al., 2000). Although such discourses may not necessarily represent nurses' actual practice, they do influence the organization of nursing practice and are taken up by nurses in various ways to construct a nursing 'gaze' or lens through which nurses see health and healthcare (Canam, 2008; Cheek, 2000).

## Access to Oncology Care among Indigenous Peoples

For Indigenous Peoples in Canada, the varied and complicated range of barriers are often closely tied to colonization and neocolonial structures. Geographical location, limited primary care and diagnostic services locally, and challenges with transportation are significant barriers to accessing oncology care (Chan et al., 2020; Howard et al., 2014; Lavoie et al., 2016). Poverty, food insecurity and unstable housing mean that attention is focused on day-to-day survival rather than addressing cancer or other health concerns (AFN, 2009; Corvus Solutions, 2012; Macdonald et al., 2015; SE, 2012). Historical trauma and subsequent distrust and avoidance of western healthcare systems, and actual or anticipated experiences of racism prevent or delay access to oncology care (Bottorff et al., 2001; Brooks et al., 2014; CancerCare Manitoba, 2013; Maar et al., 2013; Macdonald et al., 2015). As providers of oncology care, nurses daily navigate the tensions between these systemic and structural forces influencing the health and healthcare access of Indigenous Peoples and the individual lives of patients experiencing cancer. As such, oncology nurses have intimate knowledge of the challenges faced by Indigenous Peoples. Yet the perspectives of oncology nurses on access to care, their work as nurses, and the context in which they deliver oncology care to Indigenous Peoples has not yet been explored. The purpose of this study was to provide a platform for the voices and perspectives of oncology nurses.

## Methodology

In this paper, I present the findings from one component of a doctoral thesis that critically examined oncology nurses' perspectives on access to oncology care among Indigenous Peoples in Canada. The multiple-methods study included a national online survey (Chapter 4) and follow-up individual semi-structured interviews, which are reported here. The

specific research objectives for this component of the study were to examine: a) how nurses understand access to and the delivery of oncology care among Indigenous Peoples; b) how nurses define their work within the delivery of oncology care to Indigenous Peoples; and c) the underlying discourses that shape both nursing practice and access to healthcare. Study design and analysis of data drew on interpretive descriptive and critical discourse analysis methods, and postcolonial theory. Ethical approval for this study was obtained from the University of Manitoba Education & Nursing Research Ethics Board, and from CancerCare Manitoba.

**Theoretical Perspectives**

Rooted in analyses of power and colonial relations (Anderson et al., 2009), this study was informed primarily by postcolonial theoretical perspectives. Emerging from multiple contexts and disciplines, postcolonial theory is less concerned with specific acts of colonization, but rather with the ways in which colonialism continues to structure present day reality (Young, 2016). Drawing attention to the social, historical, political and economic roots of inequities, postcolonial theory enables a contextual analysis of health and healthcare (Mohammed, 2006). Postcolonial theory provided a theoretical lens through which to understand multiple forms of oppression as intersecting and interlocking (Anderson, 2004; McGibbon et al., 2014). Within nursing, postcolonial theory is particularly useful in understanding how power and privilege are operating and how nurses may be participating in and reproducing taken-for-granted power structures (Mohammed, 2006), while identifying and disrupting discourses that situate health a-historically and a-contextually (Anderson, 2002). As applications of postcolonial theoretical concepts in nursing practice, we also drew on cultural safety and trauma-and violence-informed care frameworks to inform this study.

**Recruitment**

Nurses who completed a survey of their perspectives on access to oncology care for Indigenous Peoples were invited to participate in a follow-up individual semi-structured interview. Methods for recruiting survey participants are described in detail elsewhere (Chapter 4) and included email invitations to participate in a national online survey, extended to oncology nurses across Canada, in collaboration with the Canadian Association of Nurses in Oncology. Those interested provided their name and contact information to a study coordinator and were contacted by the student. Using snowball sampling methods, nurses who completed an interview were invited by email to refer interested colleagues (Appendix L). Eleven participants were recruited by email, with an addition four using snowball methods. Informed Consent Forms were obtained prior to their interview (Appendix K).

**Participants**

Fifteen participants were interviewed, all of whom were registered nurses. These nurses had an average of 17 years of nursing experience and 11 years of oncology-specific experience. All worked in a direct patient care capacity, with the majority (n=10) working in provincial cancer centers across Canada. Two thirds of nurses worked with Indigenous patients on a daily or weekly basis. The majority of nurses (n=12) identified as non-Indigenous.

**Table 1**

*Characteristics of Participants*

| **Nursing Experience** | **Years** |
|---|---|
| Average Years Nursing | 17 |
| Average Years Oncology Nursing | 11 |
| **Type of Nursing Registration** | **# of responses (%)** |
| RN | 15 (100%) |

| | |
|---|---|
| **Highest Level of Professional Education** | |
| Diploma | 2 (13%) |
| Undergraduate Degree | 10 (67%) |
| Master's Degree | 3 (20%) |
| **Type of Oncology Practice Setting** | |
| Provincial Cancer Center | 10 (67%) |
| Satellite Cancer Center | 2 (13%) |
| In-patient Setting | 3 (20%) |
| **Type of Nursing Position** | |
| Direct patient care | 15 (100%) |
| **Frequency Working with Indigenous Patients** | |
| Daily (at least once per day) | 5 (33.5%) |
| Weekly (at least once per week) | 5 (33.5%) |
| Monthly (at least once per month) | 3 (20%) |
| Occasionally (at least once per year) | 2 (13%) |
| **Ancestry** | |
| Self-identify as Indigenous (First Nations, Métis, Inuit) | 2 |
| Self-identify as other than Indigenous | 12 |
| Not identified | 1 |

**Data Collection**

Data was collected using individual, semi-structured interviews to explore nurses' perspectives on access to oncology care for Indigenous Peoples. Interviews were conducted in person (outside of the participant's work environment) or via telephone, depending on their personal preference or geographical location. A semi-structured interview guide included general questions about the participant's nursing practice environment, education, and memorable experiences caring for Indigenous patients with cancer. As the interview progressed, nurses were asked about perceived barriers to Indigenous patients accessing oncology care, examples of patients who received high- or low-quality care, and their perspectives on how access to oncology care could be improved (Appendix N). Participants received a $25 gift card in recognition of their time. Interviews were digitally audio-recorded and transcribed verbatim.

**Data Analysis**

Interpretive description and critical discourse analysis informed the approach to data analysis (Cheek, 2000; Thorne, 2016), which aimed to: 1) describe how nurses understand barriers to accessing oncology care among Indigenous Peoples and their role in shaping access, and 2) analyze the discourses shaping nurses perspectives on access to care and the delivery of oncology care to Indigenous Peoples. Transcribed interviews were imported into NVivo® to organize and sort the data. Data analysis progressed over several stages; first, transcribed interviews were read in their entirety to gain a sense of the whole. Next, codes were formed by identifying key words, phrases or ideas; categories were subsequently developed by identifying patterns within the coded data which were expanded, collapsed, and refined iteratively (Thorne, 2016). In the final stages, I moved toward a more abstract, conceptual analysis, with the aim of addressing the research questions and identifying clinical implications relevant to nursing practice.

Using critical discourse analysis approaches, nurses' use of 'language' or ways of talking were explored. Drawing on Foucauldian notions of discourse and power (Cheek 2000; Foucault, 1977), particular attention was paid to the 'unwritten rules' and underlying assumptions present, the effects of those assumptions, and how those assumptions shaped the clinical practice setting and constructed barriers to healthcare access. Postcolonial theory drew attention to broader systems of power at the macro level, the organization of healthcare systems and clinical practice at the meso level, and clinical encounters at the micro level. Incorporating cultural safety and trauma-and violence-informed care frameworks focused the analysis on the impact of relationships between healthcare providers and patients on access to care. This study is a component of a dissertation and therefore, the analysis was primarily the

work of the student; however, analytic insights and emerging themes were discussed with and shaped by a team of expert researchers, two of whom are nurses. An audit trail of analytic insights and interpretive decisions was maintained throughout the analysis. The findings were also critically appraised by two Indigenous healthcare providers with knowledge of the oncology context, which further enhanced the credibility and relevance of our findings.

## Findings: Access Denied

Access to oncology care was influenced by a number of intersecting barriers. Nurses saw this as a broken system and viewed themselves as working within the limits of that system. The ways in which nurses and other healthcare professionals interacted with and constructed Indigenous patients contributed to gatekeeping processes that denied access to care. Multiple competing discourses also shaped access to oncology care and nurses' ability to impact access, primarily through an emphasis on 'task-based care' and a corresponding discounting of relational, culturally safe care.

### The System is Broken

The healthcare system broadly, and oncology system specifically, is complex, intimidating, and does not work well for Indigenous Peoples. Nurses described the system as "broken", "fractured", and "a mess". Within a fragmented system that functions in silos, patients can – and do – easily fall through the cracks. Nurses highlighted how lack of communication and coordination between parts of the system created further barriers to accessing oncology care, particularly for those living in northern or remote locations, where primary care settings are plagued with high staff turnover and inconsistent access to care. Those who worked as oncology nurse navigators were acutely aware of the barriers facing Indigenous Peoples: "that's why I have a job, right? Like literally. Because it's a broken

system" (I12). Although nurses described a multitude of barriers to accessing oncology care (see Table 2), the degree of 'brokenness' was not necessarily related to the number or type of barriers, but rather to the ways in which barriers *intersected* with one another. Particularly salient in the nurses' narratives of access to care was the profound impact of culturally safe care (or lack of) on accessibility, which further magnified other access challenges.

**Table 2**

*Barriers to Accessing Oncology Care*

| **Barrier/ Description** | **Description** | **Example** |
|---|---|---|
| **Communication** | Difficulty communicating with patients in ways that impede access to care or reduce quality of care | No central communication tool for patients moving between specialized oncology care and primary care within the community (I02) |
| **Fear** | Patient experience of fear that prevent them from accessing care | Fear of healthcare providers related to how they may be treated or received by people (I05) |
| **Healthcare provider understanding** | Lack of understanding among healthcare providers of the historical and current context of Indigenous Peoples | Nurses lacking basic education on Indigenous Peoples' context; for example, not knowing what a reserve is (I02) |
| **Jurisdiction** | Jurisdictional ambiguities or disputes that impact access to care, specifically for registered First Nations peoples, who have some healthcare services funded by the federal government, and some by the provincial government. | Disagreement between the federal and provincial governments regarding who would pay for the patient's transportation to their reserve community (I14). |
| **Lack of care coordination** | Disconnect between healthcare providers or between parts of the system impacting access to care | Patients discharged from hospital who require follow-up from multiple allied health professionals (e.g., speech-language pathology, dietician), and transported home without any supportive or follow-up care arranged (I02) |

| | | |
|---|---|---|
| **Patient location** | Patients living in rural, remote or isolated geographical locations | Few specialized oncology services are available in non-urban locations, and often Indigenous patients are travelling long distances every time care is needed (I06) |
| **Policy** | Policies that prevent or delay access to care | Non-insured health benefits (NIHB) placing restrictions on funding for medical transportation (I02) |
| **Patient context** | Access to resources and the social determinants of health (transportation, financial, education, primary care, etc.) | Housing insecurity, lower income levels, higher levels of poverty, which may correspond to different literacy rates, all of which impact an individual's ability to access care (I15) |
| **Understanding of the healthcare system** | Patient or family's knowledge of the healthcare system | Unfamiliarity with the healthcare system or 'language' of healthcare means that some patients are unsure how to navigate the system, or unsure of even what they could be asking for in terms of care (I11) |
| **Self-advocacy** | Patient or family's ability to advocate for self | Patients who are able to advocate for themselves are typically able to access the care they need, whereas patients who are less able to self-advocate have more difficulties accessing care (I03) |
| **Systems** | The design/structure/ nature of the healthcare system | The healthcare system functions in 'parts' or silos. Cancer patients typically have many appointments with many different providers and can easily fall through the cracks (I15). |

***Barriers to accessing care are layered and compounding***

Throughout the interviews, many nurses highlighted the intersectional nature of access to oncology care, describing how, for many Indigenous patients, barriers to accessing care are "layered" upon one another. One nurse provided a poignant example from her clinical experience:

> This client had attended the nursing station first to try and access some support for trying to determine what was making them so unwell. Immediately, in that encounter, the client was viewed as drug seeking and, unfortunately, you know, the typical thing that would happen to him when he had actually had multiple encounters trying to get some support, he had been given a couple of Tylenol 3s and sent home. The symptoms didn't improve. They only became worse […] At one of the visits, they had said "okay, we'll send a requisition in for a scan", and that was like six or eight months down the road. And a lot of that had to do with whatever was written on that requisition. And that's again a barrier to how that client is going to get to their care. So he couldn't get to anything else – he physically could not get to another option, unless he got creative, which he did. He was an elderly man, so this was quite significant for him to go outside of his community, find a way to get outside of his community […] So he sought care in an emergency department in a northern setting. They again considered him drug seeking […] But they did prescribe him something different for the pain and had ordered another scan. And this one was going to be done sooner, but he had to find a way of staying in that city because now the person that he came with [as an escort] went home. The federal system, non-insured health benefits, were only going to provide him coverage while he was an escort […] So he found a place to stay. He couch surfed. Again, an elderly gentleman couch surfing… And finally, he went back into the emergency room again before his scan, and they decided to scan him. They called a nurse navigator in the community immediately, who called me, about concerns she had because she had done an initial kind of review of the case. He had six metastatic fractures and a large tumour. (I13)

The nurse went on to point out how issues of racism and assumptions on the part of healthcare providers intersected with geography, policy and multiple other barriers to repeatedly deny the patient access to care.

Other nurses described poverty, mental health and addictions issues and trauma as barriers that tend to intersect with others to reduce or prevent access to care. Several nurses emphasized that not only are the barriers themselves problematic, but that the layering of barriers has a compounding effect that severely limits access to care.

***Lack of culturally safe care negatively impacts access***

Nurses described how the lack of culturally safe care created barriers to accessing oncology care. Examples of racism, labelling, judgment, dismissal of health concerns, and disrespectful interactions were brought forward as barriers to accessing care:

> I think [discrimination] definitely affects access. I think that's why when you look at our people as a population we show up in later stages of cancer. And I think that a lot of that is because of the discrimination that people feel within the system, the institution kind of thing and the mistrust, and so people leave it until it's so far gone that they can't tolerate it anymore […] I just spoke to a lady a couple of days ago that knew for two years something was wrong with her and she kept going to her doctor in the north and he just kept telling her it was in her head […] two years later she's full of cancer (I02).

Nurses in this study identified racism, both interpersonal and systemic, as impacting access to care. Some nurses used terminology of "institutionalized" (I12) and "structural" (I15) to communicate the systemic nature racism, with one nurse eloquently describing racism as just "the water in which we swim" (I13). Other nurses described witnessing racism within their oncology practice setting, and described the profound impacts that these experiences within the healthcare system have on patients, including deep-seated fear or distrust of healthcare providers, "because of how they may or not be treated or received by people" (I05). More importantly, lack of culturally safe care is not simply a 'one-off' experience, but is layered with repeated experiences of racism over a lifetime, and the experiences of family members including parents and grandparents, within the historical context of colonial relationships between the Canadian government and Indigenous Peoples.

**Working Within the Confines of a Broken System**

Although nurses described a healthcare system that is broken, they also described the ways in which they are able to work within those confines to support Indigenous patients in accessing oncology care. Nurse navigators, in particular, were emphasized by many of the

participants as essential in bridging gaps in care. The nurses found creative 'work arounds', pragmatic solutions, and were resourceful in collaborating across disciplines or institutions to address gaps in care. For example, one nurse told the story of a patient living in a remote northern community who was receiving a monthly subcutaneous injection (usually a 15 minute appointment) that required her to take a 4 hour flight to the nearest city, stay overnight, and return home the next day; the travel burden created significant stress for the patient and made it difficult for her to maintain employment. The nurse worked with provincial oncology pharmacists, the oncology institution and a local airline to establish a way for the injections to be delivered by air to the patient's community and administered to the patient locally. Other nurses spoke about the importance of coordinating care on behalf of patients and helping patients to navigate the system, however at times this took a patronizing tone: "they kind of almost need a little bit more hands-on care. Like, I need to know where you're staying to make sure that you're getting from here to here at the right time" (I11).

***"There are limits to what we can do"***

While nurses worked within, and sometimes around, the limits of the system, they were also limited in what barriers to accessing care they were able to address within their practice. Beyond time constraints within busy clinical settings, which were cited as problematic, some nurses expressed frustration at the lack of input into larger systems of policy and decision-making. For example, several nurses discussed decisions made by the Non-Insured Health Benefits (NIHB) program that severely limited patient access to services, and how they felt these decisions were often arbitrary and made exclusive of their input and expertise. Nurses who described caring for patients with a history of trauma were left feeling overwhelmed and under-resourced, and unable to provide the care necessary. One nurse

described a clinical situation in which a patient, who did not have family support or stable housing, and who had experienced significant trauma including a sexual assault, required a diagnostic colonoscopy. The nurse spent many weeks establishing a relationship of trust with the patient and coordinating multiple aspects of her care but could not move the patient through the diagnostic phase: "As a navigator, you're supposed to have all the tools in your toolkit, to take the next step. But sometimes you're just…like I can't make that part happen. I can't make them see a counsellor" (I10). While recognizing the significant social and structural barriers facing their patients, this was accompanied by a recognition that *they alone* would be unable to fully address such issues: "I can pull all the resources I can, and I can't level that playing field" (I04).

**Hidden Processes of Gatekeeping Deny Access to Care**

Nurses described how healthcare providers, positioned as experts who can speak authoritatively within the patient-provider relationship, function as 'gatekeepers' who allow or deny access to the healthcare system. Gatekeeping was accomplished through multiple mechanisms, both overt and covert:

> The healthcare system is the authority. And if they allow or offer or reject or decline, that really is something that [patients] don't have a lot of control over. They can advocate, but to a large extent they really have to go along with whatever is provided or not provided to them (I05).

Some nurses described a mechanism of gatekeeping in which healthcare providers (usually physicians, in their examples) did not present all relevant cancer treatment options to patients who were Indigenous, particularly to those who lived long distances from cancer centers:

> A second- or even third-line treatment might mean more doctor's visits down in [city], more time spent away from home when the prognosis maybe isn't that great. And so it might get presented in a little bit different way to somebody who is living up north (I11).

These nurses perceived that treatment options were 'filtered' based on the potential of the patient to complete the treatment, or the support and resources the patient had access to. One nurse described a more subtle way this occurred, in which the oncologist interacted with patients who were Indigenous in a way that "broke the relationship at the outset" (I12). The nurse suggested that the mannerisms and subtly insensitive way in which treatment was offered resulted in patients who were Indigenous declining treatment. Other less overt mechanisms of gatekeeping included discourses of legitimacy and compliancy among oncology care providers.

***Discursive constructions of legitimacy***

The hierarchy of healthcare relationships, in which providers are positioned as 'experts', allows healthcare providers to judge the validity (and therefore legitimacy) of patients' health needs and, consciously or not, decide whether those needs should be met. One nurse perceived an unwritten expectation within western healthcare institutions that patients who encounter the system must be "articulate about why they have come to access care" (I12); in other words, they must present themselves, through their talk, as legitimate patients. Several nurses depicted clinical scenarios in which the needs of an Indigenous patient were not being met, and how their physical presence as nurses within the hospital or exam room, or their advocacy on behalf of the patient, changed the way the patient was treated, and sometimes, how their specific needs were perceived and/or addressed:

> "The quality of care improves when other healthcare staff know there's someone supporting that patient, who has their back. So I think by having specific Indigenous support in oncology, it makes everyone else a little more aware of how they're interacting, how they're treating and how they're speaking with that patient" (I01).

Constructions of legitimacy also occurred in interactions between oncology nurses and NIHB: several nurses described having to communicate about patients in ways that NIHB "find meaningful" or "agree with" in order to secure coverage of various medical expenses (I02, I13). For example, patients' requests to have an 'escort' (a family member to accompany them to appointments) is often not constructed as a valid need:

> "When I've talked to patients on the phone to give appointments or to talk about their consultation, they've asked […] can you make it sound really serious so that they'll give me an escort? And it's like, you shouldn't have to beg for an escort and make it sound serious. You have cancer" (I06).

Access to resources and healthcare services is therefore denied in some cases, based on the perceived legitimacy of the patient's need.

***Constructing the non-compliant patient***

Nurses' accounts of clinical encounters revealed the discursive construction of patients as compliant or non-compliant; this was evident not only through some nurses' descriptions of their own clinical care, but more often in the interactions they witnessed and spoke of. Compliant patients – those who followed prescribed medical care – were described as "positive", "cooperative", "appreciative", and "not angry or defensive" (I05, I09, I15). A specific issue that was raised repeatedly was that of missed or refused appointments. For example:

> The staff deemed her [an Indigenous patient] uncooperative because they had arranged for her to have a last-minute procedure on a Friday afternoon and of course she had medical transport [back to her reserve community] so she has to catch her van at a certain time. And so she declined the procedure. And they kind of labelled her as uncooperative […] Well if she doesn't get on that van and go home for the weekend then she has no money and no hotel in the city (I02).

Implied in the constructions of non-compliant patients was a judgment of those patients as irresponsible or lazy, and correspondingly, less deserving of care. As a form of discipline, patients who missed appointments were deemed non-compliant and were either denied another appointment or were given restrictive limits on the number of times they were allowed to reschedule, regardless of the contextual circumstances or barriers faced. Labelling patients as non-compliant seemed to be a mechanism of power through which healthcare providers could set the (unspoken) rules of engagement, establish and maintain their position within the hierarchy of the healthcare system, and in some cases, limit access to care.

**Biomedical Discourses Dominate Healthcare Contexts & Constrain Access**

The collective of discourses common within biomedicine come together to create a 'gaze' or lens that impacted the ways in which nurses spoke about and understood healthcare, prioritizing efficiency, neutrality, and the diagnosis and treatment of body parts. While the effect of biomedical discourses was evident in the way nurses spoke, there were some who explicitly acknowledged and resisted these discourses:

> We like to put everybody into a box. It's a respiratory problem. It's an oncology problem. It's a gastro problem. It's a mental health problem. But with Indigenous and

> the social determinants of health, you can't just sandwich everything into one box. It's layers and layers of different effects" (I01).

Through a biomedical lens, illness tends to be compartmentalized and attributed to individual 'lifestyle choices', while health is conceptualized narrowly. Nurses acknowledged how such narrow conceptualizations of health risks further marginalizing Indigenous Peoples from the healthcare system, thus impeding access to care. For example:

> We tell them what should be important to them…they have a lot of healthcare interactions where they're told 'Here's what you're doing wrong' or 'here's what you need to do' or 'here's what's really important'. And what if that's not their priority? (I06)

The impact of biomedicine was also evident in discourses of task-based nursing, in which 'good' or 'important' nursing care was seen as that which was tangible. One nurse insisted that because she worked in an outpatient clinic setting which does not involve hands-on cancer treatments, "I don't actually give them care" (I09). Task-based nursing discourses also manifested in the way nurses prioritized the physical and technical over other aspects of care:

> You have another patient that you're responsible for and they might be really sick that day, or you need to get those meds, and so I think that's a really tangible [thing]. It's like, there is just not enough time in the day to try to give more time to someone else (I07).

Task-based discourse also became apparent through descriptions of everyday nursing practice, with nurses commenting on the ever-expanding requirements for documentation and

assessment in the form of checklists or screening tools. A focus on tangible tasks drew nurses' attention away from the important relational and psychosocial aspects of nursing care.

**Pursuing Cultural Safety/Trauma-and Violence-Informed Care**

While biomedical discourses were evident in the data, nurses' accounts of working with Indigenous patients with cancer also demonstrated their resistance to biomedical discourses through their pursuit of culturally safe and trauma-and violence-informed care. Through narratives of the importance of building relationships with patients, establishing trust, and taking time with patients, nurses countered biomedical discourses of efficiency, objectivity and neutrality. A focus on the relational aspects of nursing care challenged the prioritization of physical care:

> I think any relationship with a patient that is fulfilling is because you've come to know the patient. And it's not just about giving good physical nursing care. It's more the mental health, or the – just having a relationship with that patient (I11).

Narratives of the importance of recognizing and addressing one's own biases, providing respectful care and creating safe clinical spaces as ways to improve access suggest an implicit understanding of the principles of culturally safe care. Nurses acknowledged how trauma and structural violence also impact Indigenous Peoples disproportionately and influence how healthcare is accessed. One nurse discussed the ways in which historical realities continue to shape current healthcare experiences among Indigenous Peoples (I14). In her experiences as a pediatric oncology nurse, she came to understand how healthcare institutions have been a place where Indigenous children have been apprehended and removed from their families, making parents fearful of accessing the healthcare system. She further emphasized that current healthcare access cannot be abstracted from historical conditions. Considering the

social and structural barriers faced by each individual patient contested the individualist perspectives that are the hallmark of biomedical discourses:

> Health is not just a construct of how your physiology is functioning and what your anatomy is, but it's so much more than that. It's the context in which we live and all of the factors that really are part of who we are and how we experience the world around us […] If we're thinking about barriers, even recognizing personal barriers, system barriers, structural barriers, if we even looked at things a little bit differently to identify these things, we might be able to move through it differently (I13).

Although discourses of cultural safety (CS) and trauma-and violence-informed care (TVIC) were evident in nurses' narratives on access to care, there was a palpable tension as biomedical discourses competed to structure the way nurses thought about and valued CS and TVIC as important, but less important than tangible nursing tasks. One nurse described taking extra time to develop trusting relationships with patients, particularly those who were Indigenous, which often meant working longer hours. She clearly saw value in this, yet also commented that "it's not necessarily a super use of my time as a nurse" (I04). Another nurse described working with an Indigenous patient, who confided to her about the healing he was experiencing through the Truth and Reconciliation Commission:

> And I thought, my God, this man, he's confiding this stuff in me. And it just took me a moment to listen to him and to really appreciate what was happening, what it meant for so many people… And I didn't do anything. I just sat and listened (I10).

Here, the work of listening, engaging, and developing relationships is languaged as 'not doing anything', thereby discounting the important relational and psychosocial aspects of nursing care.

## Discussion

This study investigated nurses' understandings of access to oncology care for Indigenous Peoples. Examining access to care from the perspectives of oncology nurses provided a window into the world of oncology nurses, which facilitated an exploration of the discourses shaping their practice, and subsequently, access to oncology care. The nurses in this study shared a good understanding of the complex nature of healthcare access among Indigenous patients, and of the social and structural determinants of health that was not just theoretical, but also steeped in their clinical and experiential knowledge.

The healthcare system was described as broken, and nurses understood barriers to accessing oncology care as intersecting and compounding. Young (2001) provides an analogy that is helpful in understanding individual barriers as a *system of oppression* by asking us to imagine a birdcage: examined individually, each wire of the birdcage does not limit the bird from flying. However, examined as a whole, "a large number of wires arranged in a specific way and connected to one another to enclose the bird and reinforce one another's rigidity can explain why the bird is unable to fly" (Young, 2001, p. 10). Seen through this lens, the findings from this study shed light on how multiple intersecting barriers form a system of oppression that denies Indigenous Peoples equitable access to care. Furthermore, these 'wires' or barriers are systematically arranged in a way that suggests the system is not broken but is actually functioning exactly as it was designed to.

Nurses shared examples of culturally unsafe care and identified systemic racism as a significant challenge in accessing oncology care for Indigenous patients. This adds to the growing body of research over the past several decades that has highlighted the pervasiveness of racism within the Canadian healthcare system (Allan & Smylie, 2015; Browne & Fiske,

2001; Royal Commission on Aboriginal Peoples, 1996; Tang & Browne, 2008; Wylie & McConkey, 2019). Lack of culturally safe care, however, should not be understood as something that is merely absent, but as care that is *unsafe* and as perpetuating the structurally violent conditions already experienced by Indigenous Peoples. Cultural safety (CS) and trauma- and violence-informed care (TVIC) have been proposed as ways of enacting social justice at the point of care, and as approaches to care that promote equitable and accessible healthcare services (Browne et al., 2016; Health Council of Canada, 2012; Levine et al., 2020; Papps & Ramsden, 1996; Public Health Agency of Canada, 2018; Yaphe et al., 2019). Nascent research suggests that training in CS and TVIC increases healthcare providers' understanding of health inequities, awareness of power differentials, capacity for self-reflection, and responsiveness to racism, trauma, and oppression (Browne et al., 2018; Kurtz et al., 2018; Levine et al., 2020; Masinde, 2017; Yaphe et al., 2019). Moreover, incorporating CS and TVIC training challenges dominant biomedical approaches to care and can stimulate organizational change (Browne et al., 2018; Levine et al., 2020). Despite such promise, the findings from this study suggest that CS and TVIC can be difficult to integrate in healthcare contexts. Nurses are increasingly expected to incorporate CS into clinical practice, yet few formal structures exist to support this type of nursing practice (Hole et al., 2015; Levine et al., 2020). Nurses in this study who described caring for patients who had experienced trauma in their lives were left feeling overwhelmed and unsupported, which raises the question of what can reasonably be expected of nurses, and what structures and systems are needed to support nursing practice that is culturally safe and trauma-and violence-informed.

Although findings from this study provide evidence of culturally safe care and TVIC within clinical oncology nursing, discourses of CS and TVIC competed with biomedical

discourses to structure nurses' talk: the relational and psychosocial aspects of care were constructed as less important, while tangible nursing care and tasks were given priority. Tension between competing discourses makes it difficult for healthcare providers to prioritize relational aspects of care within a health system dominated by a biomedical model (Foster, 2017; Masinde, 2017; Yaphe et al., 2019). Discrepancies in the way nurses would like to provide care and what they are actually able to do frequently manifests in insufficient attention to care that is non-physical, and results in distress among nurses (Beagan & Ells, 2007; Varcoe & Rodney, 2009; Varcoe et al., 2012). When nurses do engage in relational work, it is often discounted or seen as 'doing nothing' by the healthcare team, but also, and more importantly, *by nurses themselves* (Canam, 2008; Coombs, 2004; Varcoe & Rodney, 2009). Cheek (2000) notes that because the relational work of nurses is often not valued by nurses, they do not document it, thus rendering nurses' efforts in providing care that is culturally safe and trauma-and violence-informed completely invisible. If social justice values are truly at the heart of nursing, we as nurses must critically question the devaluing of our relational work, and the institutional and systemic constraints that limit our ability to practice in accordance with our values.

Beyond competing with CS and TVIC discourses, the impacts of biomedical discourses were evident elsewhere in the findings. Biomedical discourses are akin to what Smith (1999) conceptualizes as the 'ruling relations', or systems of regulation and control mediated through discourse. Specifically, the monitoring and surveillance of patients (especially those referred to as 'marginalized') to ensure conformity to the norms and expectations is a mechanism of power and control – or gatekeeping – mediated through discourse (Hall, 1999). Lupton (1995) observes how nurses' charting reveals the tendency

among nurses towards an "obsession with the close scrutiny of patients' lives that is often judgmental" (p. 161). This manifested here through discourses of compliancy, where patients' attendance at appointments was not only closely monitored, but also disciplined. Exclusionary appointment booking practices focused not on ensuring optimal healthcare access, but on limiting access to healthcare for those patients who did not adhere to the 'rules of engagement'. Such disciplinary practices can also be linked to efficiency discourses, where the goal of cost constraint limits the number of appointments a patient can miss or reschedule. Ironically, the findings in this study suggest that it is the biomedical 'gaze' – the construction of a patient as a disease to be treated without consideration of the social and structural barriers to accessing care – that has led to the 'inefficiency' of missed appointments in the first place.

The impact of biomedical discourses on nurses' work and working conditions is profound, and evidence suggests that nurses take up these discourses even when they do not necessarily adequately or accurately reflect nursing practice (Canam, 2008; Cheek & Rudge, 1994; Cheek, 2000; Coombs, 2004; Dahlke & Hunter, 2020; Varcoe & Rodney, 2009). Nurses, therefore, are upholding and perpetuating the very structures that discount their work and limit their ability to practice in ways that accord with their values. Yet nurses *do* have agency and *are* capable of critically examining the conditions of their work (Varcoe & Rodney, 2009). While nurses' work is regulated and constrained through discourse, their *agency* is also accessible through discourse (Dahlke & Hunter, 2020; Smith, 1999). McGibbon and Lukeman (2019) argue that "language becomes the terrain where nurses either support or resist ruling relations that operate to create and sustain oppression" (p. 5). Levine et al. (2020) recommend explicitly attending to the dominant worldviews within the clinical practice setting. The findings presented here suggest that nurses can and do practice in ways

that foster relationship and address the social and structural determinants of health, but do not necessarily recognize the constraints on their practice. I suggest that a starting point would be for nurses to recognize that there *are* dominant discourses shaping their practice, and that these discourses have tangible impacts on equitable access to care. Subsequently, I advocate for oncology nurses to use language that explicitly identifies structural barriers to healthcare access, and to name lack of equitable access to oncology care for Indigenous Peoples as a form of oppression.

### Strengths & Limitations

The results of this study should be considered in light of several strengths and limitations. Participants in this study were experienced and well-educated nurses working in a range of practice and geographical settings. All participants had firsthand experiences of delivering oncology care to Indigenous Peoples; six participants identified themselves as nurse navigators, and as such, brought an additional depth of knowledge and experience of systems and structural issues. While the perspectives of these 15 nurses are not necessarily representative of all oncology nurses, listening to their insights and experiences does raise some important questions and challenge current understanding of CS practices. Further research is needed in diverse oncology settings to better understand how nurses can be best supported in delivering equitable oncology care, and the role of the profession in redressing health inequities among Indigenous Peoples in Canada.

## Conclusion

Despite a growing body of evidence identifying the barriers to accessing oncology care among Indigenous Peoples, few studies have sought the perspectives of nurses. This examination of nurses' perspectives demonstrates the importance of CS in ensuring equitable

access to oncology care among Indigenous Peoples, and the impact that individual healthcare providers, including nurses, can have on facilitating or denying access to care. These findings challenge popular discourses in Canada that all healthcare contexts are culturally unsafe, as the narratives of nurses revealed evidence of their pursuit of CS and TVIC in oncology settings. However, the hegemonic presence of biomedical discourses competed with discourses of CS and TVIC to discount the relational work of nurses. Explicit analyses of the impacts of CS and TVIC on healthcare access, and the mechanisms needed to support such nursing practice, at both the institutional and systems level, are urgently needed. Furthermore, nurses must recognize and call out the ways in which powerful discourses shape not only their practice, but access to care itself, and, along with multiple intersecting barriers, form a system of oppression. Nurses must therefore consider the ways in which they may be actively redressing inequitable access to care, or actively perpetuating such inequities by supporting the status quo. The social justice work of nurses must necessarily focus not only on collectively questioning a healthcare system in which racism is the norm and structural violence further entrenches inequities, but the ideological and structural constraints on nursing practice itself (Varcoe & Rodney, 2009).

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# Chapter 6: Conclusion

The overall aim of the thesis was to critically examine access to oncology care among Indigenous Peoples in Canada, with a specific focus on the perspectives of and impact of oncology nurses. This critical examination unfolded through 4 distinct approaches, which have been addressed in chapters 2 – 5. In this chapter, I present an overview of key findings from each chapter, followed by a discussion that synthesizes findings from the individual chapters. In this discussion, my aim is to demonstrate the contributions of the findings to advancing knowledge on access to oncology care for Indigenous Peoples in Canada. Based on this discussion, I draw attention to key implications for nursing practice, advocacy and education, along with directions for future research.

## Overview of Key Findings from Chapters

In this thesis, I set out to address the following objectives: 1) to identify, summarize and analyze what is currently known about access to oncology care among Indigenous Peoples in Canada; 2) to theorize the role of nurses in improving access to care; 3) to explore how nurses understand access to oncology care; and 4) to explore how nurses understand their role in delivering oncology care to and improving access to care for Indigenous Peoples. I begin here by highlighting notable findings from each chapter which address the stated objectives.

### Chapter 2: Access to Cancer Care among Indigenous Peoples in Canada: A Scoping Review

The scoping review provided a map of current evidence on access to oncology care among Indigenous Peoples in Canada and documented notable gaps in research in this field. A key finding of scoping study was that only a third of studies included identified barriers to

accessing oncology care at the structural level. Notably, some structural barriers, such as racism and poverty, were framed in some studies as though they were individual or systems barriers and few studies explicitly identified colonialism as a structural determinant of healthcare access. This suggests that although there may be increasing awareness of 'social' determinants of health, there is less understanding of how issues such as racism and poverty are structural in nature. It comes as no surprise then that the solutions proposed to address inequities in healthcare access, and the attention of clinicians, researchers and policy makers remain fixed at the individual level, which risks further perpetuating and entrenching inequities. In addition, the scoping study revealed a relative absence of the perspectives of nurses within the current literature. This finding in particular was a key factor in my decision to focus specifically on the perspectives of nurses and shaped the development of the multiple-methods study.

**Chapter 3: Nurses as Agents of Disruption: Operationalizing a Framework to Redress Inequities in Healthcare Access among Indigenous Peoples**

The second paper provided an overview of the frameworks of cultural safety and trauma-and violence-informed care (TVIC) and explicated how these frameworks could be applied to better understand and address inequitable healthcare access within nursing. There is a body of literature that assumes cultural safety and TVIC are one route to changing practice and improving healthcare accessibility, yet little guidance exists for nurses on how to take up these frameworks in practice. I focused my argument on how cultural safety and TVIC could be taken up by *individual* nurses to impact access to care. The resulting framework defined three domains for nursing action to specifically address inequitable healthcare access: practicing reflexivity, prioritizing relationships and considering the context. Through

highlighting the important role and work of nurses, I aimed to challenge popular discourses that equate improved healthcare access to increased funding, new healthcare facilities, or expanded physician services. The development of this framework laid the groundwork for the development of the survey and interview studies, which focused specifically on the perspectives of oncology nurses, and explored how they understood their role (or if they even saw a role for themselves as nurses) in improving access to oncology care.

**Chapter 4: A Critical Exploration of Nurses' Perceptions of Access to Oncology Care Among Indigenous Peoples: Results of a National Survey**

This paper presented the findings from a national online survey of oncology nurses. The primary contribution of this paper was to provide a snapshot of the views of oncology nurses practicing in Canada on access to care for Indigenous Peoples. Building on the findings of the scoping review, my aim in the analysis of survey responses was to consider not only the types of barriers described by nurses (i.e., individual, systems, structural), but also the ways in which they talked about accessing care, with the view that their narratives around access to oncology care would influence their views on how they as nurses could impact access to care. The most prominent finding from the survey were the pervasive narratives of individualism that drew the attention of oncology nurses towards individual, and to a lesser extent, systems level barriers to accessing oncology care. Correspondingly, there was limited insight and awareness of structural barriers, although at times the structural nature of barriers was implied by nurses. Many of the nurses in this study saw themselves as playing a role in facilitating access to care, but this was largely directed at the individual, and sometimes systems level. Although not stated as such, the dominance of the biomedical model in healthcare was felt among nurses and was implied to constrain their ability to

practice in ways that could improve access to oncology care. Interestingly, there seemed to be little awareness of the impact of racism (interpersonal, institutional or structural) as a barrier to accessing oncology care. This is a notable absence given the growing body of evidence documenting the profound impacts of racism on the health and wellbeing of Indigenous Peoples in Canada.

**Chapter 5: Access Denied: Nurses' Perspectives on Access to Oncology Care among Indigenous Peoples in Canada**

The fourth and final paper presented the findings of individual interviews with fifteen oncology nurses across Canada. Nurses in this study understood access to oncology care as layered and contextual, with barriers intersecting and compounding one another. While their understanding of access was broad and included structural influences, their work focused primarily on individual and systems-level issues. A key finding from the analysis of interview data was the hegemonic presence of biomedical discourses in oncology nursing practice. Most notably, biomedical discourses competed with discourses of cultural safety and TVIC, which had the effect of devaluing the relational work of nurses while prioritizing task-based physical care. At times, biomedical discourses were mediated through institutional 'texts'; for example, requirements for assessment and documentation in the form of clinical pathways, screening tools and checklists structured nursing practice and communicated what was 'essential' nursing work. At other times, competing discourses were evident in nurses' use of language; for example, describing their relational work while at the same time, dismissing it as 'doing nothing'. Interestingly, lack of culturally safe care was identified as a major challenge to accessing oncology care. Although nurses seemed to understand the value of cultural safety and TVIC, particularly in relation to healthcare access among Indigenous

Peoples, a key contribution of this study is a better understanding of how the discursive and organizational context in which oncology nurses work has significant impacts on their capacity to integrate cultural safety and TVIC into practice.

## Discussion of Synthesized Thesis Findings

Examining findings across chapters reveals multiple points of convergence. In this discussion, I highlight key findings from the thesis as a whole and situate these within current literature. In particular, the hegemonic impact of biomedical discourses within oncology nursing practice, the lack of attention to structural influences on access to oncology care, and the absence of nursing advocacy at the policy level are noteworthy.

### Dominance of Biomedical Discourses

The dominance of biomedical discourses, a common thread throughout the thesis, is noteworthy. Here, I am speaking of discourses as ways of thinking about reality, or as "systems of possibility for knowledge" (Cheek & Rudge, 1994, p. 584). Though often invisible, discourses provide a set of unwritten rules and common assumptions that enable some ways of thinking while excluding others (Cheek, 2000). From a Foucauldian perspective, discourses are inextricably linked to power and are thus constantly vying for status (Cheek & Rudge, 1994; Hall, 2001). Yet not all discourses hold equal weight: the specific discourses afforded dominance at any given time are a result of power relations and political interests (Cheek, 2000). As the predominant model of health and illness within Canada (and indeed much of the Western world), biomedicine considers the individual as the source of health and illness, abstract of any social, economic, political or historical influences, while reducing the focus of healthcare to treatment of organs and bodily systems (Bolaria, 2009; Horrill et al., 2018; McGibbon & Hallstrom, 2012). Having gained power because of

their strong association with the 'scientific' paradigm (Canam, 2008; Raphael & Curry-Stevens, 2016), the dominance of biomedical discourses lies not necessarily in their 'truth', as there is substantial evidence regarding the impact of social structures on health, but in their ability to limit or relegate other ways of knowing about health and healthcare to the margins (Cheek, 2000). While a full discussion of the evolution of 'scientific' medicine and the associated rise of physician dominance in healthcare is beyond the scope of this chapter (see for example, Bolaria, 2009), the important point here is that biomedical discourses do not allow for an understanding of the complex and intersectional relationships between the social, historical and political contexts that impact health (Reimer-Kirkham et al., 2007).

Since the time of Nightingale, the profession of nursing has maintained that it holds specialized nursing knowledge, independent of biomedical knowledge, typically considered the domain of physicians (Risjord, 2010). Although the domain and extent of nursing knowledge has been the subject of extensive debates over the past century, this knowledge is clearly explicated, for example, through the ethnographic work of nurse scholars (see for example: Allen, 2015; Coombs, 2004; Rankin & Campbell, 2006). At the same time, this unique nursing knowledge has been and continues to be colonized[3] by biomedical discourses (Holmes et al., 2008; McGibbon et al., 2014). This has occurred to the extent that biomedical discourses "pervade all spheres of nursing: research, education, administration, and practice" (Holmes et al., 2008, p. 42). For decades, nurse scholars have documented the ways in which nursing knowledge, and as a result, nursing practice, are compared with and subordinated to

[3] In this discussion, I use the concept of 'colonizing' to represent a dominating or controlling force. I do not use this term to minimize the devastating impacts of settler colonialism, nor to imply that as professionals, nurses have experienced colonization like that of Indigenous Peoples.

biomedical knowledge (Canam, 2008; Cheek & Rudge, 1994; Coombs, 2004; Dahlke & Hunter, 2020; Street, 1992). As Cheek (2000) notes,

> nursing is often positioned and portrayed with respect to its relation to scientific/medical discourse rather than in terms of *nursing* discourse… How nurses and nursing are portrayed, both by themselves and by others, is to a large extent the result of powers and practices that operate to position nursing in one way rather than another (p. 24, emphasis mine).

The effects of the power relationship between biomedical and nursing discourses can be seen in, for example, the prioritization of physiological treatments and technical or task-oriented nursing care over relational or psychosocial care (Canam, 2008), or in the shift away from models of clinical management that center nursing and patient care to models that center organizational and business goals (Allen, 2015; Rankin & Campbell, 2006). The concern here is not the technical care that nurses expertly provide, but rather, that biomedical discourses exclude other important aspects of nursing care and fail to adequately represent the full breadth and complexity of nursing practice, which necessarily draws upon multiple ways of knowing (Holmes et al., 2008; Reimer-Kirkham et al., 2007).

In this thesis, the impact of biomedical discourses on the delivery of healthcare services and the work of nurses was evident in both the online survey and interviews with oncology nurses. Prioritization of physical care, perceived lack of power within the healthcare hierarchy, and a corporatized model of healthcare with an associated focus on efficiency (pressure to accomplish more tasks in less time while providing care as cheaply as possible) meant that the work of oncology nurses was organized in very specific, yet tacit ways. Although not explicitly instructed to do so (by administrators, nurse managers or other

members of the healthcare team), some nurses felt as though they could not practice in ways that fostered trusting relationships or allowed them to attend to the broader context of patients' lives. There was a deep sense of frustration among many of the nurses in this study that they desired something different within their practice, although this was often articulated succinctly as 'lack of time'. Their desire for relational connection with patients was a means to address the full spectrum of patient needs, but also as 'fuel' to keep them going. Some nurses, particularly those who participated in the interviews, were acutely aware of the need for trusting, reciprocal relationships within the context of histories of trauma, racism and structural violence among Indigenous Peoples.

The constraining impact of biomedical discourses on the work of oncology nurses is particularly concerning when it comes to considering equitable access to care for Indigenous Peoples and other groups experiencing structural inequities. The existence of trusting relationships between patients and healthcare providers, and the ability to attend to other health and social needs of patients who are marginalized are known to improve access to care (Browne et al., 2016; Wylie, McConkey, & Corrado, 2019). Yet within the context of biomedical discourses, these are the very aspects of nursing care that are deemed unimportant and as interfering with the 'efficient' processing of patients through the healthcare system (Dahlke & Hunter, 2020).

**Discourses of Individualism and Lack of Structural Attention**

The findings of this thesis suggest that many nurses, particularly those who responded to the survey, tended to frame access to care as an individual responsibility, reflected in statements about non-compliance, missing appointments, or affording medications. Alternatively, findings from the interviews suggested that many of these nurses understood

access to care as layered, and described the intersecting and compounding nature of barriers to accessing care. In the research realm, however, findings from the scoping review also demonstrated an inclination to focus on individual level barriers to accessing oncology care. The range of studies reviewed in the scoping study garnered the perspectives of both patients and healthcare providers, which included nurses, physicians, allied health, community health workers, social workers, health administrators at the local and regional levels, and government officials at the local, provincial and federal levels. Thus, the lack of attention to structural barriers to accessing oncology care is not unique to nurses. Moreover, given the growing attention to determinants of health frameworks within nursing, medical, and allied health education and practice, it is unlikely that those involved in the provision of oncology services are completely unaware of structural barriers to accessing care. Because many of the solutions to addressing systemic and structural barriers lie outside of the purview of the healthcare system or beyond the scope of individual providers, it is possible that despite an awareness of such barriers, healthcare providers may narrow their focus to only those barriers that they are able to influence. Indeed, several nurses interviewed highlighted the Non-Insured Health Benefits program as a significant policy barrier to accessing oncology care among Indigenous Peoples, yet felt they lacked any form of recourse or influence to address it.

However, strong discourses of individualism are also at play, which correspond with the lack of attention to structural influences on access to oncology care seen in the findings. As a key tenet of the biomedical model, individualism tends to view health and illness as primarily a responsibility of the individual, with a focus on behavioral risk factors and bodily systems (Browne, 2001; Raphael, Curry-Stevens, & Bryant, 2008). Discourses of individualism are not surprising when nurses and other healthcare providers, immersed in a

healthcare system built on the biomedical model, begin to speak the language of biomedicine. Although nurses may see and feel structural influences on health and healthcare access, discourses of individualism leave little room to consider, or more importantly, question such influences.

Individualism, consistent with neoliberal political ideology in which problems rooted in social structures are framed as individual problems, permeates nearly all aspects of Western society (Raphael & Curry-Stevens, 2016; McGibbon & Hallstrom, 2012). Browne (2001) notes that individualism is "so intricately woven into the fabric of Western society" that it becomes nearly impossible to recognize the extent to which it shapes our realities (p 129). What insights might we glean from a critique of the influence of individualism? Health and healthcare access, when framed as individual problems, lead to solutions that target individuals. When such solutions prove ineffective, the individual tends to be reproached for their poor health or 'unwillingness' to access healthcare; this cyclical pattern further reinforces and entrenches health and social inequities. Importantly, individualism impacts nurses' ability to consider and therefore address systemic and structural barriers to healthcare access. I am not suggesting that oncology nurses should bear the full responsibility for redressing inequities in access to oncology care. As individuals, oncology nurses are not empowered nor equipped to address the full range of systemic and structural barriers to accessing care. Yet the inability to see the broader context of health, or implicitly conveying blame, for example, pollute the relational space and dissolve trust, which negatively impact healthcare access. Although not equipped to address such broad issues on their own, oncology nurses could have a significant impact by raising their collective voices or through their

professional nursing organizations, if they have a view of health and healthcare access that extends beyond the individual.

**Absence of Racism**

The palpable lack of attention to racism as a factor impacting access to oncology care for Indigenous Peoples within the survey findings was noteworthy. This was especially surprising given the ever-growing evidence, both within research and media reports, of the ubiquitous nature of racism towards Indigenous Peoples in healthcare encounters that seriously compromises healthcare access. Elsewhere, racism was identified as a barrier to accessing oncology care in the scoping review, albeit often framed at the individual level.

How is it possible that although widely documented, racism remains largely invisible and unacknowledged as a determinant of health and healthcare access? Although the impacts of racism on access to care were discussed by nurses in the interviews, the relative silence regarding racism as a determinant of heath and healthcare access within the survey responses and scoping review is likely a product of the limited understanding of racism within Canada. Individualism comes into play here as well, where racism, if seen at all, is seen as a specific act perpetrated from one individual towards another, rather than as systemic and embedded in all aspects of society, including nursing practice (Waite & Nardi, 2017). Multiple discursive mechanisms that dismiss or downplay racism are also at play (DiAngelo, 2018; Henry & Tator, 2006; Hilario et al., 2018). In addition to the discourses of political correctness and egalitarianism (discussed in Chapter 4), discourses of denial are a central controlling mechanism within Canadian society, which purport that racism could not exist within a liberal democratic society espousing egalitarian values (Henry & Tator, 2006; Hilario et al., 2018). Discourses of colour-blindness are used by individuals to insist that they do not ‘see’ race,

and therefore, racism cannot exist (Henry & Tator, 2006). Yet racism is deeply rooted in our society and in all processes of socialization, both within and outside of the healthcare arena (Allan & Smylie, 2015; Schroeder & DiAngelo, 2010). The absence of racism in the findings suggests we still have much work to do in nursing education and practice – if we do not see the systems of racism embedded in our nursing practice and in our healthcare systems, we cannot begin to dismantle them (Hall & Fields, 2013; Waite & Nardi, 2017).

**Absence of Nursing Action and Advocacy at the Systems and Structural Levels**

Findings from the thesis suggest that oncology nurses see themselves as playing a role in mediating access to care, and use strategies primarily directed at the individual and systems levels. Not surprisingly, given the dominance of biomedical discourses and associated narratives of individualism, there were few nods to strategies targeting the structural level, such as changing policy or addressing systemic racism. While oncology nurses identified strongly with the role of advocate, this seemed to be limited in both the survey responses and interviews to advocating on behalf of individual patients. This included advocating for access to specific resources, timely access to care, specialist referrals, pain control, and prescription medications. Only a handful of nurses identified advocacy roles beyond the patient level by identifying the need for systems change (e.g., expanded cancer prevention and diagnostic services in remote areas) or policy change (e.g., subsidizing healthy food). Notably, although the structural constraints on nursing practice were evident in the narratives of oncology nurses, advocacy or action targeting the structural conditions of their work was not discussed. Given the potential for nurses, as the largest body of regulated healthcare providers in Canada, to use their collective voice to impact healthcare systems and policy, these findings are disappointing.

## Implications

The findings from this thesis demonstrate that healthcare access continues to be primarily understood at the individual patient level, and strategies that nurses take up to address inequities in access to care are similarly focused. The predominant focus at the individual level is deeply embedded within nursing and healthcare, in practice, research and policy (Reutter & Kushner, 2010). Yet what is urgently needed to address persistent health inequities is a shift in focus towards the structural conditions that determine health and healthcare access (Pauly et al., 2009). Such refocusing could be aided by attention to nursing practice and practice contexts, advocacy at the policy level, and associated changes in nursing education. In the discussion that follows, I highlight several key implications for growth and development within these key areas, and corresponding directions for future research.

### Implications for Nursing Education

Nursing education could play a significant role in addressing the need within the profession to more fully consider structural influences on health and healthcare access, and our role as nurses in responding to these determinants of health. Nursing practice is primarily focused on individual patients, with some general acknowledgement, although limited, of broader social factors that may be shaping health and healthcare access (Pauly et al., 2009; Reutter & Kushner, 2010). This is likely related to the predominant focus within nursing education on skills acquisition and committing lists of the social determinants of health to memory (McGibbon & Lukeman, 2019). Findings from this thesis suggest that although many oncology nurses are *aware* of structural factors impacting access to care, they locate and speak about those factors at an individual or systems level. This may be related to how nurses are educated, but could also be reflective of how nurses understand their sphere of

influence. A comprehensive approach to addressing inequities in health and healthcare access among Indigenous Peoples should begin in undergraduate nursing education, by infusing clinical training with a structural focus (Metzl & Hansen, 2014). It is imperative that basic nursing education include a history of the colonization of Indigenous Peoples in Canada which explicitly links past and ongoing colonial actions to the present-day health and social inequities seen in this population (Beavis et al., 2015). Importantly, structural content should be integrated longitudinally throughout undergraduate nursing education and should be developed and delivered in collaboration with Indigenous Peoples (Beavis et al., 2015). Such integration would ensure that nurses not only have theoretical knowledge of structural influences on health and healthcare access, but also understand the roles that nurses, and the profession of nursing can play in addressing these issues.

Canada's national framework for nursing education specifies addressing health disparities and social justice as essential components of nursing practice (Canadian Association of Schools of Nursing, 2015), yet an underlying disconnect between a social justice ethos and socially just nursing practice exists (Blanchet Garneau et al., 2018; Browne & Reimer-Kirkham, 2014). Issues of social justice, racism, power and privilege may be entirely absent or only briefly covered in undergraduate nursing education (Bell, 2020; Blanchet Garneau et al., 2018; van Herk et al., 2011). Rather than fostering the capacity for ongoing critical reflexivity, nurses are left to explore these issues on their own, with few resources to support their efforts (van Herk et al., 2011). In this thesis, lack of attention to racism as a barrier to oncology care in the survey responses was notable and concerning. This suggests the need for explicit attention in nursing education to racism as a structural determinant of health and healthcare access.

To address this gap, Blanchet Garneau and colleagues (2018) have proposed a critical anti-discriminatory pedagogy for nursing that aims to foster transformative learning and the development of "praxis-oriented critical consciousness" (p. 3). This approach challenges narratives of individualism through explicit attention to structural conditions and power dynamics, and systematically includes content related to anti-racism and anti-discrimination (Blanchet Garneau et al., 2018). The extent to which students are able to understand and take up content related to anti-racism and anti-discrimination, however, will depend on the comfort level and experience of nurse educators, who may feel unprepared and uncomfortable teaching content related to power, privilege and racism (Bell, 2020). With this in mind, it may be insufficient to implement curriculum changes that educators are unprepared or unable to teach. However, there is also great opportunity, particularly for white faculty, to teach nurses at the undergraduate level that "dismantling racism is an essential nursing intervention for health" (van Herk et al., 2011, p. 37). Critical to moving forward as a profession are nurses who recognize and challenge racism in nursing practice, which requires nursing education that explicitly addresses issues of power, privilege, and 'race' (Scammell & Olumide, 2011). These capacities, coupled with an in-depth understanding of the structural roots of health and healthcare access could also better enable nurses to take up their role as advocates at all levels of the healthcare system.

This is a tall order for nurse educators, given the current realities. Foth and Holmes (2016) argue that models of nursing education have shifted significantly, coinciding with the rise of neoliberalism and increasing business orientation of healthcare environments. With the introduction of competency-based education, nursing education is now tailored to meet the needs of managers, administrators and the market (Foth & Holmes, 2016). Foundational

nursing skills, including relational practice, have been reduced to “personal qualities” that are the responsibility of the individual nurse to nurture and improve (Foth & Holmes, 2016). Within a competency-based system of education, “the development of a critical, oppositional perspective becomes more challenging, if not entirely impossible” (Foth & Holmes, 2016, p 8). In light of these observations, a critical examination of current models of nursing education may be required to interrogate whose interests current models of nursing education are serving.

### *Research Implications*

There is limited evidence regarding the most impactful ways to incorporate education regarding structural determinants of health, cultural safety, TVIC, anti-racism and other critical approaches to care within nursing education. The literature to date has largely focused on the theoretical and conceptual development of these approaches. Research is needed to determine the most effective pedagogical strategies for teaching critical approaches to care that will ensure they are taken up in practice. For example, research to better understand how nursing students best learn about and subsequently incorporate cultural safety into their practice is needed.

## Implications for Nursing Advocacy

Findings from this thesis suggest that oncology nurses see themselves as advocates, but their advocacy is most often limited to the clinical context. While the work of nurses largely focuses on the health and illness of individuals and communities, it must also focus on the *conditions* that create health and illness (Falk-Rafael, 2005). The advocacy work of nurses must therefore also target the structural determinants of health (Buck-Mcfadyen & Macdonnell, 2017; Weitzel et al., 2020). Reutter and Kushner (2010) argue that “policy

advocacy is *the* strategy to reduce inequities" (p. 275). Working to care for individuals while also advocating at the policy level need not be mutually exclusive (Reutter & Kushner, 2010). Falk-Rafael and Betker (2012) call this the 'trombone slide' of nursing: working 'downstream' to alleviate illness and suffering while working 'upstream' to address the social and structural determinants of health. Among Indigenous Peoples, health and social policies are known barriers to accessing oncology care (Lavoie et al., 2016; Sayani, 2019; Tobias et al., 2020), yet cancer policies and plans rarely incorporate structural determinants of health or have clearly defined equity goals (Carter et al., 2009; Sayani, 2019). This represents a significant opportunity for oncology nurses and oncology nursing organizations to advocate for policy change.

Expectations that nurses advocate for social justice are threaded throughout nursing guidelines, standards of practice and codes of ethics (Buck-Mcfadyen & Macdonnell, 2017; Thompson, 2014). Beyond a professional obligation, nurses also bear witness to social injustice and health inequities in their everyday practice, making them not only well-positioned to advocate at the policy level, but also morally obligated to do so (Falk-Rafael, 2005; Falk-Rafael & Betker, 2012; Weitzel et al., 2020). This 'witnessing' or experiential knowledge also provides fuel for the advocacy work of nurses and gives nurses credibility in political arenas (Falk-Rafael & Betker, 2012). First-hand knowledge of the challenges faced by their patients makes nurses poised to be "solution providers" in the policy arena (Ridenour & Trautman, 2009, p. 360). Coupled with credibility and power in numbers as the largest group of regulated healthcare professionals in Canada, there is tremendous potential for the profession of nursing to be formidable advocates for social justice (Spenceley et al., 2006; Thorne, 2014; Weitzel et al., 2020).

Yet findings from this thesis highlight a concerning lack of advocacy at the policy level. This may be because as individuals, nurses feel uncomfortable and ill-prepared for this kind of work (McGibbon & Lukeman, 2019; Reutter & Kushner, 2010; Spenceley et al., 2006). Many nurses see themselves as disempowered and removed from policy, with a fundamental disconnect existing between what nurses are expected to do in terms of advocacy, and what they actually do (Spenceley et al., 2006). Thorne (2014) argues this is because as nurses, "we have been so entrenched in a disempowered collective identity that we have ignored opportunities to capitalize on our numbers and our unique wisdoms in becoming a sophisticated and effective force for public policy and health care change" (p. 86). Others have argued that healthcare reforms in Canada, including corporatization, fiscal restraint policies, a focus on efficiency, heavy workloads and burnout among nurses further discourage nurses' efforts in policy advocacy (Buck-Mcfadyen & Macdonnell, 2017; McGibbon & Lukeman, 2019; Reutter & Kushner, 2010; Spenceley et al., 2006). Lack of preparedness for policy advocacy is also related to the limited education nurses receive in relation to advocacy at the policy level (Reutter & Kushner, 2010).

The lack of advocacy at the policy level as a strategy to redress inequitable access to oncology care demonstrated in the findings of this thesis, and elsewhere in the nursing literature, has several important implications. Orienting nurses towards advocating for policy change must begin in undergraduate nursing education and continue in graduate nursing education (Buck-Mcfadyen & Macdonnell, 2017; Reutter & Kushner, 2010). Nurses should be equipped not only with the theoretical knowledge necessary but also with experiential learning opportunities and knowledge of what actions they could reasonably take. This could include asking students to write an op-ed or letter to the editor, attend a rally, or become

involved in a professional nursing organization or an institutional nursing practice council, or having students analyze the policy implications at the patient level (Buck-Mcfadyen & Macdonnell, 2017; Reutter & Kushner, 2010). By integrating conceptual knowledge and opportunities for action throughout nursing curricula, we could raise up nurses to see nursing as an "inherently political profession" (Webber, 2011, p. 145). However, questioning the ways in which nurses are *informally* taught about their advocacy role is also essential. In a recent commentary, Chen (2015) argues that although nurses are taught to develop leadership and advocacy skills in the "abstract sense", they receive contradictory messages in practice, where "silence, obedience and conformity are the desired behaviors" (p. 10).

There is also a danger in expecting nurses to enact advocacy as individuals. A key aspect of equipping nurses for policy advocacy is to focus on the collective advocacy voice by ensuring that nurses understand the importance and role of professional nursing organizations, beginning at the undergraduate level, and throughout their careers (Thorne, 2014). As nurses, we have the existing infrastructure to support policy advocacy collectively through our professional nursing organizations; as individual nurses, it is our role to ask questions of our nursing organizations, focus their attention on policy advocacy and ensure they are a voice in public policy debates (Spenceley et al., 2006; Thorne, 2014).

### *Research Implications*

If policy is a key mechanism to reduce inequities in health and healthcare access, then additional policy analysis research is needed in the area of oncology care and Indigenous Peoples. Specifically, policy documents (e.g., provincial cancer plans) that guide the delivery of care to Indigenous Peoples should be carefully critiqued for the ways in which equity is conceptualized, is or is not operationalized, and is or is not explicitly evaluated. Policy

research conducted by nurses that clearly links political ideology and social determinants of health with health inequities could further support the policy advocacy work of nurses (Reutter & Kushner, 2010).

**Implications for Nursing Practice**

Findings from this thesis suggest that lack of culturally safe care is a significant barrier to accessing care. Research in Canada provides strong evidence regarding the impact of racism and discrimination on healthcare accessibility and experiences of care (Browne et al., 2011; Ford-Gilboe et al., 2018; Goodman et al., 2017; Kitching et al., 2020; Monchalin et al., 2020; Phillips-Beck et al., 2020; Tang & Browne, 2008; Wylie et al., 2019; Wylie & McConkey, 2019). While it may be tempting to scapegoat nurses as the 'problem' to be fixed, nursing practice is highly contextual and dynamic, with the organizational context and socialization processes having significant impacts (Varcoe et al., 2003; Rankin, 2009). Calls for nurses whose discriminatory and racist behaviors garner national media attention to be fired as *the* solution to redressing the systemic and sustained racism will not, on their own, be effective. While behaviors such as these require discipline and remedial action, it is imperative that as nurses, we begin to look more broadly at the systems in which we are operating. By 'systems', I am not referring to the healthcare system, *per se,* although we should be looking at that too. I am referring to the social structures, discourses and power relations that permit racism and culturally unsafe care to be enacted and sustained within healthcare contexts.

While equity-oriented care approaches such as cultural safety and TVIC hold promise for addressing racism, mitigating unequal power relations, and drawing attention to structural determinants of health, the integration of these models of care into clinical practice must also

be critically considered. In this thesis, analysis of interviews with nurses demonstrated their pursuit of culturally safe and trauma- and violence-informed care, but also the ways in which their ability to provide this type of care was limited by biomedical discourses, and constraints at the organizational and systems levels. If the development of trusting relationships between patients and healthcare providers is the most important strategy to improving access to care for Indigenous Peoples (Wylie et al., 2019), these findings suggest the need to consider what mechanisms are needed to support the integration of cultural safety and TVIC into practice.

The uptake of cultural safety and TVIC are determined to some degree by sociopolitical and organizational contexts and shifts at the organizational level are required to re-orient services towards equity (Ford-Gilboe et al., 2018; Levine et al., 2020; Markoff et al., 2005). This has not yet been studied within the context of oncology care, however, evidence from the fields of primary and mental health care can provide some important insights into the mechanisms and policies needed to enhance organizational capacity for equity-oriented care. As a starting point, this should include an assessment of policies, procedures, organizational mission statements, performance or quality indicators, and physical environments with a view to identifying changes needed to support integration of cultural safety and TVIC (Browne et al., 2018; Ford-Gilboe et al., 2018; Levine et al., 2020; Markoff et al., 2005). Organizations can further improve their ability to address structural determinants of health and respond to the unique needs of Indigenous Peoples by building alliances with community organizations (Baum et al., 2013; Yaphe et al., 2019). Guerra and Kurtz (2017) note that while cultural safety training is integrated into many undergraduate nursing programs and continuing education programs, it remains "futile if not mandated within healthcare organizations, authorities and all levels of government" (p. 140). Including an assessment of an

organization's equity-responsiveness as a standard for healthcare institution accreditation could further encourage alignment of the healthcare system with equity goals and improve access to care. Funding models within healthcare – where funding is primarily allocated for clinical services and biomedical treatments – also present organizational and structural challenges to implementing cultural safety and TVIC; consideration of models that better support equity-oriented care is warranted (Lavoie et al., 2018; Levine et al., 2020).

The challenges in integrating cultural safety and TVIC into nursing practice, and in particular, the devaluing of relational nursing practice discussed in the findings, were not entirely external, however. The analysis of interviews with oncology nurses indicates that the devaluing of relational practice was occurring among *nurses themselves*. These findings suggest that analyses and critique of the unspoken values within clinical nursing practice and the structural conditions of nurses' work are needed (Beagan & Ells, 2007; Street, 1992; Varcoe et al., 2012). Dahlke and Hunter (2020) argue that nurses' use of language in their everyday practice reinforces the dominance of task-based discourses, while at the same time, nurses' compliance with these discourses leads to the devaluing of the full scope of nursing practice. Advocating for structural change to support nursing practice will require that we learn to articulate the value of the full scope of nursing work (Dahlke & Hunter, 2020), and that we learn how to effectively advocate at the structural level.

### *Research Implications*

Critical research within the context of oncology care is relatively sparse. To better understand and address the complexities of inequities in health and healthcare, research investigating the institutional practices, social norms and discourses that allow racism to be enacted and the processes by which 'race' and racialization are impacting access to oncology

care and cancer outcomes among Indigenous Peoples are needed. There is limited research focusing on inequitable access to oncology care among Indigenous Peoples, and further research is needed that focuses at a systems level to map patient journeys and specify problematic points. For example, 'long wait times' are frequently cited as a barrier to accessing oncology care, yet these are only vaguely identified, non-specific, and therefore difficult to address. Complex analyses that identify specific points of inequity, and how these are further compounded by structural determinants of health, could highlight impactful areas for intervention.

There is evidence that equity-oriented models of care improve patient experiences of healthcare, patient satisfaction, accessibility of care, and health outcomes within the primary care setting, however, impacts within the oncology setting are not known. Future research should explore the impact of equity-oriented care on healthcare accessibility, experiences of care and health outcomes within the context of oncology care. In addition, the lack of support for oncology nurses to practice cultural safety and TVIC highlight an important gap in the literature, and the specific frameworks and policies needed are not well understood. Future research should explore the nature and extent to which organizational and sociopolitical contexts impact the integration of cultural safety, TVIC and other models of care oriented towards improving health equity within the context of oncology care and determine the organizational and structural supports needed to enhance the capacity for equity-oriented oncology care.

## Knowledge Translation & Dissemination of Findings

Study findings will be disseminated in multiple ways. While chapters 2 and 3 are published, findings not yet published will be published in peer-reviewed nursing and/or health

journals. Locally, study findings will be presented in collaboration with CancerCare Manitoba and/or the Canadian Oncology Nurses Association (CANO) Manitoba Chapter. Study findings will also be presented to the local research community (University of Manitoba) at the Ongomiizwin annual Indigenous Health Research Symposium and/or through the College of Nursing's Helen Glass Research Symposium. A plain language summary of study results will be written and distributed to relevant health policy decision-makers, at the local and provincial level. Study results will be presented at a national or international research conference, which may include: (a) the CANO conference (held annually in October), which attracts several hundred oncology nurses from across Canada, including those practicing in clinical settings and research settings; (b) the Oncology Nursing Society (ONS) annual congress, a North American conference similar to the CANO audience (held annually in April or May; and (c) the International Institute of Qualitative Methodology's Qualitative Health Research Conference, which attracts a dynamic mix of health researchers from across multiple disciplines (held annually in October). As a result of the current pandemic, knowledge exchange and conference presentations may be delivered virtually and/or in webinar format.

## Strengths and Limitations

The aim of this thesis was to critically investigate access to oncology care among Indigenous Peoples, from the particular vantage point of oncology nurses. The everyday practice of nurses sits at the intersection of the intimate personal lives of patients and the broader systems and structures in which patients live and access healthcare. Nurses, therefore, bring important perspectives from their unique standpoint that contribute to a more nuanced understanding of healthcare access. To date, the voices of nurses regarding issues of access to

oncology care are largely absent within the extant literature. Opening space to hear the voices of nurses on this important issue is a significant strength of this thesis. The key contributions that oncology nurses could make towards addressing inequities in access to oncology care were explicated through the proposed framework, which highlights practical and pragmatic steps that nurses can take in any setting. The surveys and interviews provide a window into the working world of oncology nurses and gain important insights on the challenges they perceive, the ways in which they seek to redress inequities in healthcare access, and the obstacles they encounter in their work. This thesis makes a novel contribution to our understanding of access to oncology care by bringing to the forefront the voices and perspectives of nurses. Finally, oncology research is overwhelmingly biomedically focused. Employing critical perspectives throughout the thesis and developing a situated and contextual analysis of healthcare access which considers broad aspects is a strength of this work.

This thesis should be considered in the context of several limitations. The primary research studies focused exclusively on the perspectives of nurses working in oncology settings but may not represent the perspectives of other healthcare providers, administrators or decision-makers, who are differently positioned within the healthcare system, and would bring different perspectives on healthcare accessibility among Indigenous Peoples. Very few nurses in this study identified as Indigenous, which may also have impacted the findings. This study focused primarily on individual nurses, working in differing oncology contexts throughout Canada, and did not systematically investigate a particular organization, institution or province. The Canadian healthcare system is complex with the local context (i.e., institutions, provinces, health authorities) varying significantly across the country, and

making it difficult to capture a nuanced perspective on the range of challenges to accessing oncology care facing Indigenous Peoples. Finally, in the framework proposed in Chapter 3, I proposed that individual nurses could enact cultural safety and TVIC to improve access, yet findings from the survey and interview studies demonstrated that institutional and discursive constraints made this challenging. These findings highlight important limitations to this framework, which require additional research and development to further delineate the roles and responsibilities of individual nurses versus those at the organizational, systems and structural level.

## Conclusion

Action to address the inequities in access to oncology care among Indigenous Peoples in Canada is urgently needed. This thesis advances knowledge on the complexities and range of inequities in access to oncology care and the important work of oncology nurses. The body of work contained in this thesis makes a unique and important contribution to advancing the theoretical and empirical knowledge on the role of nurses in healthcare access and offers novel insights into the practice context in which they deliver care. While improving access to care alone will not ameliorate cancer disparities among Indigenous Peoples, it is a step in the direction of equity and towards justice.

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## Appendix A – Biomedical and Postcolonial Perspectives and Implications on Access to Healthcare

| | Biomedical | Postcolonial |
|---|---|---|
| **Conceptualization** | • Access as an individual responsibility<br>• A-contextual | • Access as a social responsibility, and form of social relationship<br>• Healthcare spaces as a social space<br>• Social, historical and political context important |
| **Barriers to Access** | • Geographical location<br>• Availability of services (primary care, screening and preventative care<br>• Availability/retention of healthcare providers<br>• Financial (ability to pay for non-insured care) | *Social*<br>• Previous negative experiences in healthcare (racism, discrimination, fear of judgment) → delays in seeking care, discourages trust in healthcare providers<br>• Language barriers<br>• Ongoing colonial relations within healthcare system and institutions reflected in 'othering' mentalities<br><br>*Historical*<br>• Legacy of colonization leading to distrust in government provided healthcare<br>• Historical trauma leading to delays and difficulties accessing care<br><br>*Policy*<br>• Variation in healthcare benefits depending on location of residency; patchwork policy<br>• Federal/provincial jurisdictional ambiguities |
| **Solutions** | • Increase services provided<br>• Increase healthcare providers<br>• Increase awareness of available healthcare services<br>• Increase funding for medical transportation | • Create socially accepting, safe and inviting spaces to reduce social distance<br>• Investment in decolonizing education, research and healthcare practices. Cultural safety as one decolonizing strategy<br>• Coordinate policy between levels of government |

**Table reproduced from:**

Horrill, T., McMillan, D. E., Schultz, A. S. H., & Thompson, G. (2018). Understanding access to healthcare among Indigenous peoples: A comparative analysis of biomedical and postcolonial perspectives. *Nursing Inquiry, 25*(3), 12237. https://doi.org/10.1111/nin.12237

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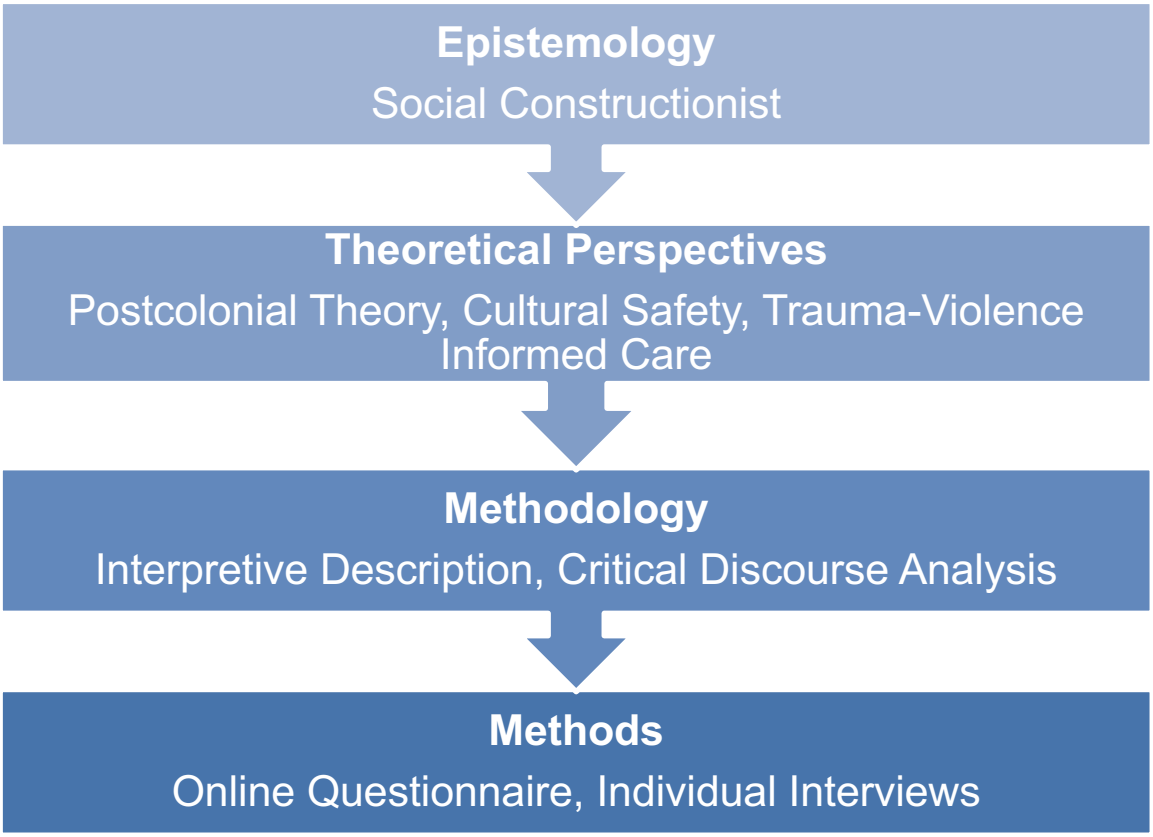
**Appendix B – Study Scaffolding**



# Appendix C – Ethical Approvals

UNIVERSITY OF MANITOBA | Research Ethics and Compliance

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

**PROTOCOL APPROVAL**

**TO:** **Tara Horrill** **(Advisor: Annette Schultz)**
Principal Investigator

**FROM:** **Joseph Gordon, Chair**
Education/Nursing Research Ethics Board (ENREB)

[redacted]

**Re:** **Protocol #E2019:011 (HS22649)**
**Access to Oncology Care among Indigenous Peoples: A Cultural Safety/Trauma Violence Informed Care Perspective**

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**Effective:** April 1, 2019 **Expiry:** April 1, 2020

**Education/Nursing Research Ethics Board (ENREB)** has reviewed and approved the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

This approval is subject to the following conditions:

1. Approval is granted for the research and purposes described in the application only.
2. Any modification to the research or research materials must be submitted to ENREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
5. A Study Closure form must be submitted to ENREB when the research is complete or terminated.
6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

**Funded Protocols:**
- **Please mail/e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer in ORS.**

CancerCare MANITOBA
ActionCancerManitoba

| Original Submission: | OFFICE USE ONLY |
|---|---|
| Yes ☒ No ☐ **If no, state RRIC # of original submission** ☐ | RRIC # 2019-07 |

## Study Submission Form
## Research Resource Impact Committee - RRIC

This form must be completed for research studies and approved by RRIC, REB and regulatory bodies before any study work is initiated. The following types of studies MUST be submitted to RRIC for review and approval:

a) studies which involve the review of CCMB patient records;
b) studies which involve any type of contact with CCMB patients (including surveys and questionnaires);
c) studies which involve the collection of tissues or body fluids from CCMB patients;
d) studies which may have significant impact on CCMB resources (staff, equipment, or other), or which may adversely affect the availability of those resources for routine patient care;
e) studies conducted by CCMB or at CCMB;
f) studies which involve CCMB data or Cancer Registry data;
g) studies which involve interviewing or surveying CCMB staff.

**For assistance with study design and analysis, click here to Email the Epidemiology department.**

1) Retroactive approval WILL NOT be granted. All impacted departments must be consulted & sign off (section 7.0).
2) Refer to the RRIC Website https://www.cancercare.mb.ca/Research/research-impact-commitee regarding the processes and guidelines for submission and review.
3) **The initial RRIC approval will be for a MAXIMUM of FIVE YEARS from the date of the RRIC approval letter. An amendment form will need to be completed at or near the study expiration date to extend the study.**

**If you have any questions regarding the forms required for a RRIC submission, please contact the RRIC Coordinator at RRIC.Coordinator@cancercare.mb.ca or 204-787-2148**

| **1.0 - Study Title and Researcher Information - All fields MUST be completed** | | | |
|---|---|---|---|
| **Study Title:** | **Access to Oncology Care among Indigenous Peoples: A Cultural Safety/Trauma Violence Informed Care Perspective** | | |
| **Principal Investigator:** | Tara C. Horrill | Institution: | University of Manitoba |
| Address: | [redacted] | | |
| Phone: | [redacted] | | |
| **Study Coordinator:** | N/A | Institution: | |
| Address: | | | |
| Phone: | | Fax: | E-Mail: |
| Correspondence to be directed to: | Principal Investigator ☒ | Study Coordinator ☐ | |

| **2.0 - Study Information** | |
|---|---|
| Study Objectives: | The purpose of this study is to generate knowledge on the role of nurses in shaping access to high quality cancer care for Indigenous peoples. The specific research aims of the study are:<br>1. To identify how nurses understand barriers and facilitators to accessing cancer care for Indigenous peoples;<br>2. To explore how nurses understand their role (as healthcare providers within a system) in shaping access to cancer care for Indigenous peoples;<br>3. To identify nursing strategies to improve access to cancer care for Indigenous peoples |
| Type of Study: ☒ Qualitative ☐ Quantitative ☐ Chart Review* ☐ Other (specify) | |
| ***A written Research Proposal is required even for Chart Reviews.** (Please refer to document "Requirements for Written Research Proposal for Chart Review" | |

| |
|---|
| *found on the RRIC website.)* |
| Where will the study be conducted: ☐ CCMB-MacCharles ☐ CCMB-St. Boniface ☒ Other (specify) University of Manitoba, Nursing |
| Does this study overlap with another study that is currently open at CCMB? ☒ No ☐ Yes (explain) |
| How will potential participants be identified and by whom? Potential participants will be identified by the ~~department of Human Resources at CancerCare Manitoba.~~ - HR not involved |
| How will potential participants be approached (by whom, where and when)? Potential participants (oncology nurses) will be recruited via email once study approval is obtained. |
| If required, who will obtain written informed consent from the participant (where and when)? Informed consent will be obtained electronically as part of the online survey. |
| Will you use CCMB space to conduct portions of your study (i.e. clinic space)? (please provide details) No. |
| Will you require the assistance of CCMB staff? No ☐ Yes ☒ (if yes, please indicate in section 7.0 - CCMB Services) |
| Will any information be sent to another centre? No ☒ Yes (explain below) ☐ |
| If yes, how will data be transmitted? (eg. Fax, E-mail, Private Courier, Canada Post Expresspost or Priority Courier, Other - Please specify) Please describe the security measures of the method used. |
| **A Supply Agreement or Data Sharing Agreement is REQUIRED for studies without contracts in which data and/or materials are to be sent to another centre. See DSA Guidelines on the RRIC website.** |

| **3.0 - Samples** | |
|---|---|
| Will samples be obtained as part of the study (eg. urine, blood, bone marrow, buccal swabs, tumour tissue, etc)? No ☒ Yes ☐ | |
| ***If no, please skip to section 4.0, otherwise, please complete the questions below.*** | |
| What type of samples will be obtained? | |
| Who will obtain the samples referred to above? | |
| When will the samples be obtained (e.g. at the same time as routine care)? | |
| Will you be obtaining samples from the Manitoba Tumour Bank? (Please see the MTB website for more information) No ☐ Yes (see below) ☐ | |
| Which bank(s) will you be accessing? Breast ☐ Lung ☐ Prostate ☐ Multiple Myeloma ☐ Ovarian ☐ CLL ☐ AML ☐ MDS ☐ Head & Neck ☐ Other (Specify) ☐ | |
| Will any samples be sent to another centre? No ☐ Yes (explain below) ☐ | |

| If yes, how will sample be sent? Please specify the methods for your transfer and the security measures of the method used. (e.g. Courier Service with proper labeling and packaging) |
|---|
| |

**A Supply Agreement or Data Sharing Agreement is REQUIRED for studies without contracts in which data and/or materials are to be sent to another centre. See DSA Guidelines on the RRIC website.**

| **4.0 - Research Funding and Contracts** | | | | |
|---|---|---|---|---|
| Is the study grant funded? | No ☐ | Yes* ☒ | Granting Agency: | University of Manitoba |
| ***Please include a copy of the grant budget as an attachment** | | | | |
| Is the study funded by industry? | No ☒ | Yes ☐ | Company Name: | |
| Is there a contract for the study? | No ☒ | Yes ☐ | | |
| Is there a budget for the study? | No ☐ | Yes ☒ | | |
| Is this study a pharmaceutical/private industry study? | No ☒ | Yes** ☐ | | |
| ****A fee of $500.00 per study is applicable for all pharmaceutical/private industry studies.** ***Please make cheque payable to CancerCare Manitoba*** | | | | |

| **5.0 - Trainee** | | | |
|---|---|---|---|
| 5.1 Is the researcher a trainee? | No ☐ | Yes ☒ | If yes, refer to 5.3 |
| 5.2 Are any trainees involved in the project? | No ☐ | Yes ☒ | If yes, refer to 5.3 |
| 5.3 Has the trainee form been signed by the supervisor? | No ☐ | Yes ☒ | |

| **6.0 - Study Parameters (If unknown, please consult with Cancer Registry/Epidemiology to determine accrual numbers.)** | |
|---|---|
| Estimated number of participants locally: | 50 |
| Estimated start date of study: | April 15, 2019 |
| Estimated duration of study: | 6 weeks |
| **Accurate number of CCMB paper charts required: | 0 |
| ****Note: You must contact Cancer Registry to obtain accurate numbers, please do not estimate.** | |
| Planned start date for chart pulls (if applicable): | |
| Planned end date for chart pulls (if applicable): | |
| Have you involved a statistician/epidemiologist in the project prior to submission? | No ☒ Yes ☐ If yes, please answer 6(i) and 6(ii) |
| 6(i) What input has been obtained thus far? | |
| 6(ii) Who has been involved in the project thus far? | |
| Please describe the plan for data analysis and who will be assisting with the data analysis: | Qualitative methodologies will be used for data analysis (i.e., patterns will be developed by clustering coded data into meaningful groups; themes will be constructed based on the patterns identified) and are described in detail in the study proposal. |

**7.0 - CCMB Services**

Will CCMB services be used? No ☐ Yes ☒ **If yes, please fill out the table below to request specific services.**

**NOTE: Approval signatures from impacted departments will be obtained during review process. Please do not contact departments for approval.**

| Department | Service Required | Contact Person | Signature | Date |
|---|---|---|---|---|
| ☐ **Cancer Registry/ Epidemiology** | ☐ Require access to Cancer Registry Database<br>☐ Mail Outs<br>☐ Assistance with study design<br>☐ Assistance with data analysis<br>☐ Project folder on CCMB secure network drive<br>☐ Access to Cancer Registry data from MCHP | Sheila Fukumura 204-787-2157<br>Dr. Kathleen Decker 204-787-4933 | | |
| ☐ **Health Information Service/Health Records** | ☐ View electronic charts<br>☐ Pull/view hardcopy chart<br>☐ Retrieval of chart if off-site in storage ($16.00 fee per chart)<br>☐ Mail-outs<br>☐ PHIA related (see section 8.3) | Janice Osondu Iheke 204-787-8586 | | |
| ☒ **Nursing** | ☐ [redacted] | | | |
| ☐ **Hematology** | ☐ Draw and/or prepare samples for shipping/ freezing | Nina Kostiuk 204-787-1630 | | |
| ☐ **Chemotherapy/ Supportive Therapy** | ☐ Nursing Care | Nina Kostiuk 204-787-1630 | | |
| ☐ **Clinical Trials Unit (CTU) (includes BMT registry)** | ☐ Screen patients for eligibility<br>☐ Obtain patient consent<br>☐ Conduct patient evaluations<br>☐ Data Management<br>☐ Study activation and maintenance | Kathryn Dyck 204-787-2127 | | |
| ☐ **Screening Programs** | ☐ Require access to screening databases<br>☐ Recruit study subjects<br>☐ Assist with data analysis<br>☐ Pull charts/films<br>☐ Mail outs<br>☐ Access to Screening data from MCHP | Kelly Bunzeluk 204-788-8636 | | |

| | | | | |
|---|---|---|---|---|
| ☐ **Patient and Family Support Services** (including: - Psychosocial Oncology - Speech Language Pathology and other rehab services - Nutrition Services - Breast Cancer Centre of Hope and Patient and Family Resource Centre) | ☐ Interview patients/families<br>☐ Give potential participants info about the study<br>☐ Emotional support<br>☐ Participation in study may raise anxiety/ distress<br>☐ Studies related to nutrition<br>☐ Studies related to speech language pathology | Lorena Gerl 204-788-8313 | | |
| ☐ **Pharmacy** | ☐ Dispense medication & prep.<br>☐ Patient education<br>☐ Store/order/receive drugs<br>☐ Accountability records<br>☐ Database access | Pat Trozzo 204-787-8902 | | |
| ☐ **Medical Physics** | ☐ Preventative maintenance calibration and/or servicing of medical equipment<br>☐ Credentialing of Radiation Therapy techniques<br>☐ Incoming Inspection (electrical + CSA) of new medical device<br>☐ Design/Fabrication of device<br>☐ Submission of Radiation Therapy Techniques Data<br>☐ EDGE Linac | Dr. Boyd McCurdy 204-787-1966 | | |
| ☐ **Information Services** | ☐ Use of new software, application or new technology | John Ioculano 204-787-4649 | | |
| ☐ **Communication and Public Affairs** | ☐ Review posters<br>☐ Display posters | Ginette Bazin 204-787-1878 | | |
| ☐ **Radiation Therapy Planning** | ☐ RT treatment plans<br>☐ Quality control documentation submission | Sandra Iftody 204-787-4784 | | |
| ☐ **Radiation Therapy Treatment** | ☐ RT imaging - Simulation or Treatment Unit<br>☐ RT Treatment | Jennifer Moyer 204-787-8714 | | |
| ☒ **Human Resources** | ☐ Hire research personnel for study<br>☒ Survey to CCMB staff | Sherry Dupuis 204-787-8555 | not involved | |
| ☒ **Other, please specify: (e.g. Tumour Bank)** | [redacted] | | | |

| **8.0 - Miscellaneous** |
|---|
| 8.1 Has the study been approved by the relevant CCMB Disease Site Group (DSG) Chair or designate? No ☒ Yes (attach copy) ☐ |
| If no, please justify: Not applicable to a DSG |
| 8.2 Which University of Manitoba Research Ethics Board (REB) has the study been submitted to? |
| ☐ Biomedical REB ☐ Health REB ☒ Nursing REB ☐ Other: |

| |
|---|
| Have you received full approval from the respective REB (i.e. not conditional approval): Yes (attach copy) ☒ No ☐ |
| 8.3 All members of the Research Team, including secretaries and trainees have signed a PHIA Pledge and commit to protect our patients' personal health information. |
| No ☐ Yes ☒ If no, please access the RRIC website for CCMB's PHIA Orientation and Pledge forms https://www.cancercare.mb.ca/Research/research-impact-commitee/guidelines |

| |
|---|
| **9.0 - Enclosures**<br>**Each study MUST include 1 electronic package and 1 paper package consisting of EACH of the following at the time of initial submission (excluding the REB approval letter which can be submitted once obtained):** |
| ☒ A Protocol/Research Proposal **REQUIRED FOR ALL STUDIES**, including chart reviews. (Please refer to the document "Requirements for Written Research Proposal for Chart" found on the RRIC website.)<br>a) Have you clearly outlined who will initially provide the patient with information about the study? |
| ☒ The completed and signed CCMB RRIC Study Submission Form<br>a) Have you accurately completed Section 6.0 Study Parameters?<br>b) Have you accurately completed Section 7.0 CCMB Services to be used? |
| ☒ The Signed PHIA For Research Agreement<br>a) Question #3: Have you clearly identified ALL AGENCIES and listed the NAMES of ALL INDIVIDUALS who will have access to study data now or in the future?<br>b) Has the Principal Investigator signed the PHIA form?<br>**Please note: The Privacy Officer's signature will be obtained during the RRIC review process. Please DO NOT contact Health Records to obtain this signature.** |
| ☒ The Research Ethics Board Submission Form |
| ☒ The Research Ethics Board Letter of Approval - submit as soon as available |

| **Include 1 electronic and 1 hard copy of these in each package if applicable:** |
|---|
| ☐ The study data capture form (for chart review studies) |
| ☒ The signed Approval Form for Trainees for each trainee involved in the study (if applicable, see section 5.0 above) |
| ☐ The signed CCMB DSG Approval Form (if applicable, see section 8.1 above) |
| ☐ The CCMB Supply Agreement or Data Sharing Agreement **(for studies without contracts in which data and/or materials are to be sent to another centre. See DSA Guidelines on the RRIC website. See section 2.0 and 3.0 above.)** |
| ☐ The fully executed contract (for contract studies) |
| ☐ The website safety certification (for studies involving web-based data collection) |
| ☒ The study budget **(Please attach if the study is grant funded, see section 4.0 above.)** |
| ☒ The consent form (if applicable) |
| ☒ Questionnaires, posters, advertisements and letters to participants (if applicable) |
| ☐ The HIPC Approval Form (if accessing data from the Manitoba Health Database) |
| ☐ Any other approval forms as applicable (specify) |

2019-07

**10.0 - Signatures**

| | |
|---|---|
| Tara Horrill<br>Name of Principal Investigator (Print) | [redacted] |
| Dr. Susan McClement<br>Name of Department Head (Print) | |

RRIC Approva [redacted] Date July 3/2019

Mr. Paul Penner, CCMB RRIC Chair

## Appendix D – Oath of Confidentiality

I, _____, agree to maintain full confidentiality in regards to any and all research material received in the course of my involvement in the study entitled "Access to Oncology Care among Indigenous Peoples: A Cultural Safety/Trauma Violence Informed Care Perspective".

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual(s) that may be revealed during the collection or analysis of data.

2. To store all data and materials in a safe, secure location as long as they are in my possession.

3. To destroy all electronic files in my possession after it is no longer required as directed by the study principal investigator.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the research data to which I will have access.

_____
Signature

_____
Name (printed)

_____
Role in Study

Date: _____

## Appendix E – Full Search Strategy

**Database:** Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to April 02, 2019>

**Search Strategy:**

1 (exp Indians, North American/ or exp Inuits/ or exp Health Services, Indigenous/ or exp Ethnopharmacology/ or Athapaskan.mp. or Saulteaux.mp. or Wakashan.mp. or Cree.mp. or Dene.mp. or Inuit*.mp. or Inuk.mp. or Inuvialuit*.mp. or Haida.mp. or Ktunaxa.mp. or Tsimshian.mp. or Gitsxan.mp. or Nisga'a.mp. or Haisla.mp. or Heiltsuk.mp. or Oweenkeno.mp. or Kwakwaka'wakw.mp. or Nuu chah nulth.mp. or Tsilhqot'in.mp. or Dakelh.mp. or Wet'suwet'en.mp. or Sekani.mp. or Dunne-za.mp. or Dene.mp. or Tahltan.mp. or Kaska.mp. or Tagish.mp. or Tutchone.mp. or Nuxalk.mp. or Salish.mp. or Stl'atlimc.mp. or Nlaka'pamux.mp. or Okanagan.mp. or Sec wepmc.mp. or Tlingit.mp. or Anishinaabe.mp. or Blackfoot.mp. or Nakoda.mp. or Tasttine.mp. or Tsuu T'inia.mp. or Gwich'in.mp. or Han.mp. or Tagish.mp. or Tutchone.mp. or Algonquin.mp. or Nipissing.mp. or Ojibwa.mp. or Potawatomi.mp. or Innu.mp. or Maliseet.mp. or Mi'kmaq.mp. or Micmac.mp. or Passamaquoddy.mp. or Haudenosaunee.mp. or Cayuga.mp. or Mohawk.mp. or Oneida.mp. or Onodaga.mp. or Seneca.mp. or Tuscarora.mp. or Wyandot.mp. or Aboriginal*.mp. or Indigenous*.mp. or Metis.mp. or red road.mp. or "on reserve".mp. or off-reserve.mp. or First Nation.mp. or First Nations.mp. or Amerindian.mp. or (urban adj3 (Indian* or Native* or Aboriginal*)).mp. or ethnomedicine.mp. or country food*.mp. or residential school*.mp. or ((exp Medicine, Traditional/ or traditional medicine*.mp.) not Chinese.mp.) or exp Shamanism/ or shaman*.mp. or traditional heal*.mp. or traditional food*.mp. or medicine man.mp. or medicine woman.mp. or autochtone*.mp. or (Native* adj1 (man or men or women or woman or boy* or girl* or adolescent* or youth or youths or person* or adult or people* or Indian* or Nation or tribe* or tribal or band or bands)).mp.) and (exp Canada/ or (Canad* or British Columbia or Columbie Britannique or Alberta or Saskatchewan or Manitoba or Ontario or Quebec or Nova Scotia or New Brunswick or Newfoundland or Labrador or Prince Edward Island or Yukon Territory or NWT or Northwest Territories or Nunavut or Nunavik or Nunatsiavut or NunatuKavut)).mp. (6891)

2 exp Cancer Care Facilities/ (4972)

3 exp Medical Oncology/ or exp Neoplasms/ or cancer services.mp. (3158451)

4 cancer*.mp. (1640754)

5 neoplasm*.mp. (2657415)

6 oncol*.mp. (156667)

7 2 or 3 or 4 or 5 or 6 (3655052)

8 1 and 7 (308)

9 limit 8 to english language (303)

10 limit 9 to yr="1996 -Current" (240)

Modified from: Campbell, Sandy, Marlene Dorgan and Lisa Tjosvold. Filter to Retrieve Studies Related to Indigenous People of Canada the OVID Medline Database. John W. Scott Health Sciences Library, University of Alberta. Rev. March 8, 2016. http://guides.library.ualberta.ca/ld.php?content_id=14026803

Note: modification was change of Inuit.mp to Inuit*.mp [MeSH is Inuits]

**Database:** Ovid EBMASE and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to April 02, 2019>

**Search Strategy:**

1 (((Indigenous People/ or American Indian/ or First Nation/ or Metis/ or Eskimo/ or Inuit/ or Indigenous Health Services/ or exp Ethnopharmacology/ or Athapaskan.mp. or Saulteaux.mp. or Wakashan.mp. or Cree.mp. or Dene.mp. or Inuit*.mp. or Inuk.mp. or Inuvialuit*.mp. or Haida.mp. or Ktunaxa.mp. or Tsimshian.mp. or Gitsxan.mp. or Nisga'a.mp. or Haisla.mp. or Heiltsuk.mp. or Oweenkeno.mp. or Kwakwaka'wakw.mp. or Nuu chah nulth.mp. or Tsilhqot'in.mp. or Dakelh.mp. or Wet'suwet'en.mp. or Sekani.mp. or Dunne-za.mp. or Dene.mp. or Tahltan.mp. or Kaska.mp. or Tagish.mp. or Tutchone.mp. or Nuxalk.mp. or Salish.mp. or Stl'atlimc.mp. or Nlaka'pamux.mp. or Okanagan.mp. or Sec wepmc.mp. or Tlingit.mp. or Anishinaabe.mp. or Blackfoot.mp. or Nakoda.mp. or Tasttine.mp. or Tsuu T'inia.mp. or Gwich'in.mp. or (Han not Chinese).mp. or Tagish.mp. or Tutchone.mp. or Algonquin.mp. or Nipissing.mp. or Ojibwa.mp. or Potawatomi.mp. or Innu.mp. or Maliseet.mp. or Mi'kmaq.mp. or Micmac.mp. or Passamaquoddy.mp. or Haudenosaunee.mp. or Cayuga.mp. or Mohawk.mp. or Oneida.mp. or Onodaga.mp. or Seneca.mp. or Tuscarora.mp. or Wyandot.mp. or Aboriginal*.mp. or Indigenous*.mp. or Metis.mp. or red road.mp. or "on reserve".mp. or off-reserve.mp. or First Nation.mp. or First Nations.mp. or Amerindian.mp. or (urban adj3 (Indian* or Native* or Aboriginal*)).mp. or ethnomedicine.mp. or country food*.mp. or residential school*.mp. or ((exp Medicine, Traditional/ or traditional medicine*.mp.) not Chinese.mp.) or exp Shamanism/ or shaman*.mp. or traditional heal*.mp. or traditional food*.mp. or medicine man.mp. or medicine woman.mp. or autochtone*.mp. or (Native* adj1 (american or man or men or women or woman or boy* or girl* or adolescent* or youth or youths or person* or adult or people* or Indian* or Nation or tribe* or tribal or band or bands)).mp.) and (exp Canada/ or (Canad* or British Columbia or Columbie Britannique or Alberta or Saskatchewan or Manitoba or Ontario or Quebec or Nova Scotia or New Brunswick or Newfoundland or Labrador or Prince Edward Island or Yukon Territory or NWT or Northwest Territories or Nunavut or Nunavik or Nunatsiavut or NunatuKavut)).mp. or Canadian Aboriginal/ NOT oriental medicine/ (7160)

2 exp cancer center/ (28607)

3 exp cancer services.mp (1261)

4 cancer*.mp. (2897682)

5 exp malignant neoplasm/ (2819193)

6 neoplasm*.mp. (672079)

7 oncol*.mp. (332271)

8 2 or 3 or 4 or 5 or 6 or 7 (3841768)

9 1 and 8 (394)

10 limit 9 to (human and English language and yr=*1996 – 2018) (322)

11 limit 10 to exclude medline journals (18)

**Database:** SCOPUS

**Search Strategy:**
(TITLE-ABS-KEY ( *indigenous* OR *aboriginal* OR *"firstnations"* OR *metis* OR *inuit** ) AND TITLE-ABS KEY ( *cancer** OR *oncolog** ) AND ALL ( *canad** OR *ontario* OR *quebec** OR *bc* OR *british* OR *alberta* OR *saskatechewan* OR *yukon* OR *nwt* OR *nor thwest* OR *manitoba* OR *labrador* OR *nunavik* ) ) AND DOCTYPE ( *ar* OR *re* ) AND PUBYEAR > *1995* AND PUBYEAR < *2019* AND ( LIMIT-TO ( DOCTYPE , *"ar"* ) OR LIMIT-TO ( DOCTYPE , *"re"* ) ) AND ( LIMIT-TO ( LANGUAGE , *"English"* ) )

**Database:** EBSCOHost

**Search Strategy:**
indigenous OR aboriginal OR “first nations” OR metis OR inuit*
AND cancer* OR oncolog*
AND canad* OR Ontario OR quebec* OR bc OR british OR alberta OR saskatchewan OR Yukon OR nwt OR northwest OR manitoba OR labrador OR Nunavik

**Database:** Google Advanced

**Search Strategy:**

Cancer, services, Canada, “first nations” “first nations” OR metis OR aboriginal OR inuit* OR indigenous (limited to PDF files only)

**Appendix F – Data Extraction Form**

## Definitions

| | |
|---|---|
| **Access** | The freedom or ability to obtain or use healthcare services; mediated by the availability, cost, quality, timeliness and proximity of services, as well as the degree to which services are perceived as socially safe |
| **Cancer Care** | Any health service related to the screening, diagnosis, treatment or follow-up (survivorship care or palliative care) of cancer, regardless of setting (community, hospital, etc) |

## Inclusion/exclusion criteria

| **Criteria** | Inclusion | Exclusion |
|---|---|---|
| **Language** | English | Other |
| **Country** | Canada | Other |
| **Date** | 1996-2018 | Other |
| **Population** | Indigenous (First Nation, Métis, Inuit) | Other |
| **Focus** | Cancer services – delivery of/access to | Other (epidemiology, etiology, prevention/risk, biology, etc) |
| **Type of Publication** | Original Research | Other |

## Research Question

What are the barriers to accessing cancer-related care for Indigenous peoples in Canada? Where along the cancer care continuum do these barriers lie?

## General Information

| | |
|---|---|
| **Date form completed** | |
| **Name of data extractor** | |

## Publication Characteristics

| | **Descriptions as stated in report/paper or note otherwise** |
|---|---|
| **Authors** | |
| **Title** | |
| **Publication Year** | |
| **Type of Publication** | |
| **Journal (if applicable)** | |

## Study Characteristics

| | **Descriptions as stated in report/paper or note otherwise** | **Location in text or source** *pg & ¶/fig/table/other* |
|---|---|---|
| **Indigenous Population (FN, Inuit, Métis)** | | |
| **Type/Number/ Gender of Participants (if relevant)** | | |
| **Purpose/Aim of study** | | |
| **Methodology** | | |
| **Methods** | | |
| **What types of barriers to accessing cancer care were identified?** | | |
| **Where along the cancer continuum were the barriers?** | ☐ Screening ☐ Diagnosis<br>Type: _____<br>☐ Treatment ☐ Survivorship<br>☐ Palliative care ☐ Other: _____ | |
| **What was the outcome of encountering that barrier?** | | |

| | | |
|---|---|---|
| **What recommendations (if any) did the authors make?** | | |
| **Notes:** | | |

| **Leve of Engage-ment** | **NONE** | **INFORM** | **CONSULT** | **INVOLVE** | **COLLABO-RATE** | **LEAD** |
|---|---|---|---|---|---|---|
| **Goal of Indigenous involvement in research** | No Indigenous involvement. | To provide Indigenous peoples with information about the research project, and assist them in understanding the research problem and/or findings. Examples: meetings with Indigenous community members or Elders to inform about the research project. No control in the research process. | To obtain Indigenous feedback on the research process, data analysis, research findings, and/or decisions to implement research findings. Examples: meetings with Indigenous community members or Elders to get feedback on the research project. No control in the research process. | To work directly with Indigenous peoples throughout the research process to ensure that Indigenous concerns and aspirations are understood and considered. Examples: Indigenous advisory group; community members as data collectors. No control in the research process. | To ***partner with*** Indigenous peoples in each aspect of the research process, including the research design, execution, data analysis, interpretation and dissemination of findings. Examples: part of the research team; role in shaping the research study. Some control in the research process. | To have Indigenous peoples ***lead*** each aspect of the research process, including the research design, execution, data analysis, interpretation and dissemination of findings. Examples: leading methodological decisions, first authorship. Full control in the research process. |
| Notes: | | | | | | |

## Appendix G - Email Invitations to Participate (CANO)

**Subject**: Access to Oncology care for Indigenous Peoples Questionnaire

Dear Members,

In an effort to advance oncology research, CANO/ACIO has reviewed the study below and agrees it is suitable for sharing with our members as our members may be able to provide important information to this researcher. This does not mean CANO/ACIO is endorsing this research, nor should any member feel obliged to participate.

**Title of Project:** Access to Oncology Care among Indigenous Peoples: A Cultural Safety/Trauma Violence Informed Care Perspective

**Principal Investigator:** Tara Horrill (doctoral student in the Ph.D. in Nursing program, University of Manitoba). This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a doctoral degree in nursing. This study will be supervised by Dr. Annette Schultz.

**Who is Eligible to Participate:** Registered nurses with at least 1 year of oncology nursing experience

You are invited to participate in a questionnaire of oncology nurses in Canada. The purpose of the questionnaire and research study is to better understand the role of nurses in shaping access to oncology care for Indigenous peoples in Canada, and nurses' perspectives on the barriers to accessing oncology care among this population.

If you complete the questionnaire, you will be asked if you would like to be entered into a random draw of participants to win one of three $100 electronic gift cards to Starbucks, Amazon.ca or Chapters Bookstores.

Your response to this questionnaire is important to improving access to oncology care and decreasing cancer disparities among Indigenous peoples. Your participation is voluntary and involves completing a confidential online questionnaire which should take about 20 to 30 minutes to complete. This research is being conducted by a team of researchers at the University of Manitoba, College of Nursing. The Manitoba Centre for Nursing and Health Research (MCNHR) will manage the data in order to ensure confidentiality of participation.

Your participation would be greatly valued and appreciated. To learn more about the study, view the consent form, and complete the questionnaire if desired, please click on the following link:

(hyperlink removed)

Thank you for considering participating in this important research.

## Appendix H - Email Invitations to Participate (CancerCare Manitoba)

**Subject**: Access to Oncology care for Indigenous Peoples Survey

Dear Nurses,

You are invited to participate in a survey of oncology nurses in Canada. The purpose of the survey and research study is to better understand the role of nurses in shaping access to oncology care for Indigenous peoples in Canada, and nurses' perspectives on the barriers to accessing oncology care among this population.

**Title of Project:** Access to Oncology Care among Indigenous Peoples: A Cultural Safety/Trauma Violence Informed Care Perspective

**Principal Investigator:** Tara Horrill (doctoral student in the Ph.D. in Nursing program, University of Manitoba). This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a doctoral degree in nursing. This study will be supervised by Dr. Annette Schultz.

**Who is Eligible to Participate:** Registered nurses with at least 1 year of oncology nursing experience

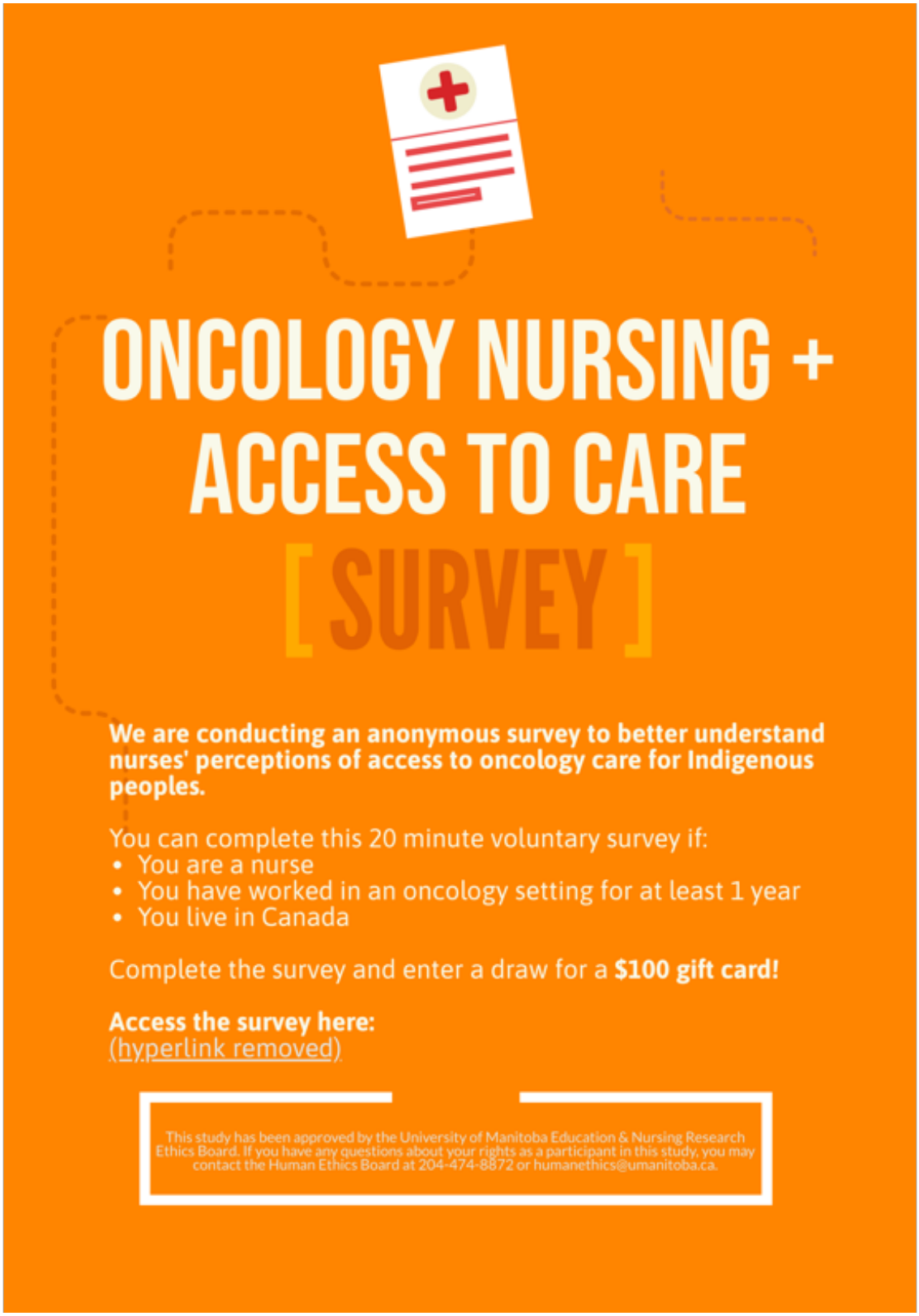
If you complete the survey, you will be asked if you would like to be entered into a random draw of participants to win one of three $100 electronic gift cards to Starbucks, Amazon.ca or Chapters Bookstores.

Your response to this survey is important to improving access to oncology care and decreasing cancer disparities among Indigenous peoples. Your participation is voluntary and involves completing a confidential online survey, which should take about 20 to 30 minutes to complete. This research is being conducted by a team of researchers at the University of Manitoba, College of Nursing. The Manitoba Centre for Nursing and Health Research (MCNHR) will manage the data in order to ensure confidentiality of participation.

Your participation would be greatly valued and appreciated. To learn more about the study, view the consent form, and complete the survey if desired, please copy and paste the following link into your browser: (hyperlink removed).

Thank you for considering participating in this important research.

**Appendix I – Recruitment Flyer**



To access the survey on your mobile device, simply hover your smartphone's camera over this code.

Questions? Need more information? Contact Tara Horrill (PhD student) at: (email address)

## Appendix J – Informed Consent Form (Survey)

**Research Project Title**: Access to Oncology Care among Indigenous Peoples – A Cultural Safety/Trauma-Violence Informed Care Perspective

**Researcher Contact Information**

**Principal Investigator:**
Tara Horrill, BN, PhD(c), RN
College of Nursing, University of Manitoba
E: [redacted]
P: [redacted]

**Research Supervisor:**
Annette Schultz, PhD, RN
College of Nursing, University of Manitoba
E: [redacted]
P: [redacted]

The principal investigator (Tara Horrill) is a doctoral student in the Ph.D. in Nursing program at the University of Manitoba. This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a doctoral degree in nursing. Her research supervisor is Dr. Annette Schultz, and her committee members are Dr. Donna Martin and Dr. Josée Lavoie.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information. To save the information contained in this consent form, please print this page for your records.

**Research Purpose**

The purpose of this study is to better understand the role of nurses in shaping access to high quality, patient-centered cancer care for Indigenous peoples in Canada. There are three specific research aims: a) to identify how you, as an oncology nurse, understand the factors that help and hinder access to cancer care for Indigenous peoples; b) to study how you, as an oncology nurse, understand your role in shaping access to cancer care for Indigenous peoples; and c) to get your perspective, as an oncology nurse, on strategies that could improve access to cancer care for Indigenous peoples.

**Study Procedures**

As a participant in this study, you are being asked to complete an online questionnaire. The questionnaire should take about 20-30 minutes to complete.

**Potential Risks & Benefits**

There are minimal risks to participating in this study, beyond the risks inherent in daily living. You may experience mild emotional distress when sharing information about a challenging or negative experience. If this occurs, you may decide to take a break and return to the questionnaire when you feel ready, or stop the questionnaire. There will not be direct benefit from participating in this study, although sometimes participants may find it helpful to talk about and share their experiences. We hope the information learned from this study will beneficial in improving our understanding of nurses' perspectives about access to oncology care for First Nations.

**Confidentiality**

All data collected from this questionnaire will be kept confidential by the researchers. All data is collected into a password protected account on Qualtrics.com which is only accessible by the Principal Investigator and supervisors listed above. After data collection is complete, all data will be downloaded from the Qualtrics website into a password protected computer in the offices of the Principal Investigator and the Research Supervisor and deleted from the Qualtrics account. No names will be stored with the data. Only the researchers named above will have access to raw data for data analysis purposes. Electronic, de-identified data will be stored in a central encrypted server. The database will have firewalls to secure all information, and allow access by authorized, password-protected user accounts only. This will ensure all study participant information remains anonymous. Information from this study may be published or presented in public forums; however, your name and other identifying information will never be used or revealed. Study findings will be reported in an aggregate form or summarized. However, we may use one of your direct quotes to illustrate a key point (no name and no identifiable features).

**Compensation**

To thank you for your participation, if you complete the questionnaire, we are offering a draw to win one of three $100 gift cards to Starbucks, Amazon.ca or Chapters Bookstore. One participant will be randomly selected from those who have participated in the questionnaire by [enter early bird date], one by [mid-point date], and one by [final date]. You will be asked at the end of the questionnaire whether you would like to be included in this draw and if so, which card you would like to receive. The Manitoba Centre for Nursing and Health Research at the University of Manitoba will notify the winners of these gift certificates using the email address you provide. The name and email address provided will be entered on a separate webpage, and will not be linked with your survey responses.

**Voluntary Participation/Withdrawal from the Study**

Your decision to participate in this study is entirely voluntary. You are free to withdraw from the study and stop the survey at any time without consequence. If you do not complete the survey, your data will not be saved. However, once you have completed the survey and click "Submit", you will not be able to withdraw your consent since survey responses are anonymous, and there is no way for the researchers to know which data are yours.

**Summary of Research Results & Dissemination of Research Findings**

The results of this questionnaire will be reported in aggregate and will not contain any individual identifiers. No individual's data will be reported. The results will be presented at scientific conferences and published in a journal so that others learn from the research. At the end of the questionnaire, you will be asked if you would like to review the preliminary study findings and/or receive a summary report of the study findings. If you indicate you would like to receive either of these reports, you will be asked to provide an email address at which you would like to receive the report. The summary report will be emailed to you by [date].

**Destruction of Confidential Data**

All personal information including names and consent forms will be kept secure in a locked cabinet at the Asper Clinical Research Institute for seven years after the study has been completed. All hard copies and electronic copies of study documents will be destroyed according to the University of Manitoba's policy about destruction of confidential material, in approximately February of 2027.

**Questions**

You are free to ask any questions that you may have about your participation in this study and your rights as a research participant. If any questions come up during or after the study, you can contact Tara Horrill at [redacted] or [redacted].

**Your participation in this questionnaire indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

**The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.**

**This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca.**

If you consent to participate, please click on the **"NEXT"** button below to begin the questionnaire.

## Appendix K – Online Questionnaire

Thank you for your interest in completed the survey, which consists of 16 questions. The first 8 questions gather demographic information, and the last 8 questions are open-ended questions where you share your perceptions of access to oncology care for Indigenous peoples in Canada. **At the end of the survey, there is an invitation to participate in an individual interview (in person or by telephone, at a time convenient to you) about access to oncology care for Indigenous peoples, which would allow you to further expand your responses.**

We would like to know a bit about your nursing background and setting. Please check the most appropriate box.

1. What type of nursing registration or licensure do you hold?
    a. RN (Registered Nurse)
    b. LPN (Licensed Practical Nurse)
    c. Advanced Practice (Nurse Practitioner, extended practice)
    d. RPN (Registered Psychiatric Nurse)
    e. Other _____

2. How many years have you been practicing as a nurse (total years in any nursing setting)? (Please round to the nearest whole year) _____

3. How many years have you been practicing as an **oncology nurse**? _____

4. What is the highest level of professional education you have attained?
    a. Diploma
    b. Bachelor's degree
    c. Master's degree
    d. Doctoral degree

5. In what type of oncology setting do you practice?
    a. Provincial cancer center (CancerCare Manitoba; Saskatchewan Cancer Agency)
    b. Satellite cancer center (community cancer clinic)
    c. Community setting (palliative care)
    d. In-patient setting

6. How often do you work with Indigenous patients in your oncology setting?
    a. Daily (at least once a day)
    b. Weekly (at least once a week)
    c. Monthly (at least once a month)
    d. Occasionally (at least once a year)
    e. Never

7. What type of nursing position do you hold?
    a. Direct patient care
    b. Supervisory (clinical resource nurse, charge nurse)
    c. Managerial
    d. Executive

8. How do you identify your ancestry?

    _____

Please think about a time when you cared for an Indigenous patient with cancer, or their family, as you answer the next few questions.

9. Take a moment to describe the clinical picture and the context of that experience.

10. Thinking about this patient or other similar patients, what barriers did this patient or their family face in accessing care for their cancer? This could be related to cancer screening, diagnosis, treatment, follow-up or palliative care.

11. In what ways were you able to assist this patient or their family in accessing the necessary care for their cancer or resources to support their cancer care?

12. From your perspective, how can nurses play a role in improving access to oncology care across the cancer continuum?

13. Please take a moment to describe what cultural safety or culturally safe care means to you.

The following audio clip provides an account of a First Nations cancer survivor's experiences of accessing cancer care. Please listen to his story, and then answer the final three questions.

14. Thinking about <u>this story</u>, what barriers did this patient or their family face in accessing care for their cancer?

15. In what ways could you as a nurse have assisted this patient in accessing the necessary cancer care?

16. What barriers do you face as a nurse in implementing the strategies you identified in question #14?

Are you interested in participating in a one-hour digitally (audio) recorded interview about your perceptions of access to oncology care among Indigenous patients? If yes, (sent to different IP location) please provide your name, email address or telephone number.

Would you be interested in reviewing preliminary findings?
If yes (sent to a different IP location), please provide name, email or mailing address.

Would you like to receive a summary of the study's findings?
If yes (sent to a different IP location), please provide name, email or mailing address.

## Appendix L – Snowball Sampling Email

**Subject**: Follow-up re: Access to Oncology Care Study

Dear (past participant),

I would like to thank you again for participating in an interview as part of my doctoral research study exploring access to oncology care for Indigenous peoples. You have made a significant contribution to this study!

I am still seeking study participants for both the survey and interview portion of my research. I would be very grateful if you could pass this email on to any of your colleagues (oncology nurses) who you think might be interested in participating in the study. The online survey, along with the consent form which further explains the study, can be accessed at: (hyperlink removed).

I am always willing to answer any questions by phone or email. I appreciate your interest in this research, and thank you for your time.

## Appendix M – Informed Consent Form (Interview)

**Research Project Title**: Access to Oncology Care among Indigenous Peoples – A Cultural Safety/Trauma-Violence Informed Care Perspective

**Researcher Contact Information**
**Principal Investigator:**
Tara Horrill, BN, PhD(c), RN
College of Nursing, University of Manitoba
E: [redacted]
P: [redacted]

**Research Supervisor:**
Annette Schultz, PhD, RN
College of Nursing, University of Manitoba
E: [redacted]
P: [redacted]

The principal investigator (Tara Horrill) is a doctoral student in the PhD in Nursing program at the University of Manitoba. This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a doctoral degree in nursing. Her research supervisor is Dr. Annette Schultz, and her committee members are Dr. Donna Martin and Dr. Josée Lavoie.

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

### Research Purpose

The purpose of this study is to better understand the role of nurses in shaping access to high quality, patient-centered cancer care for Indigenous peoples in Canada. There are three specific research aims: a) to identify how you, as an oncology nurse, understand the factors that help and hinder access to cancer care for Indigenous peoples; b) to study how you, as an oncology nurse, understand your role in shaping access to cancer care for Indigenous peoples; and c) to get your perspective, as an oncology nurse, on strategies that could improve access to cancer care for Indigenous peoples.

### Study Procedures

If you choose to take part in this study, you will be interviewed about your perspectives, as an oncology nurses, on access to oncology care for First Nations peoples. A single interview will be scheduled with Tara Horrill, the Principal Investigator, at a time that is suitable for you. You may choose to participate in a face-to-face interview in person, via Skype or FaceTime or you may choose to participate in a telephone interview. The interview will take approximately 60 to 90 minutes, and the audio will be digitally recorded. After the interview, the digital recording

will be transcribed verbatim, and assigned a code number; any identifying features have been removed by a transcriptionist who has signed an oath of confidentiality. The transcript will be read and analyzed to identify significant statements and themes by the researchers.

**Recording Devices**
A small, digital recording device will be used to record the interview.

**Potential Risks & Benefits**
There are minimal risks to participating in this study, beyond the risks inherent in daily living. You may experience mild emotional distress when sharing information about a challenging or negative experience. If this occurs, please tell Tara Horrill and you may decide to stop, take a break, or continue the interview. There will not be direct benefit from participating in this study, although sometimes participants may find it helpful to talk about and share their experiences. We hope the information learned from this study will beneficial in improving our understanding of nurses' perspectives about access to oncology care for First Nations.

**Confidentiality**
We will do everyone possible to protect your confidentiality and/or anonymity as a research participant. Your name and any identifiable features will be removed from the transcript and your name will not be used in any reports about the study. Tara Horrill will assign a study ID and pseudonym to the transcription of your interview, and this study ID will be used in data analysis and reports of the study's findings rather than your name. This signed consent form and the demographic survey (no name on this form) will be kept in separate files in a locked filing cabinet at the Asper Clinical Research Institute for 7 years following the completion of the study. In approximately February of 2027, hard copies of the consent forms and the completed demographic survey will be shredded as per University of Manitoba's protocol for destruction of confidential material. In approximately February 2027, all electronic copies of de-identified transcripts, summaries of demographic information (no names), data analysis documents will be deleted by Tara Horrill.

De-identified transcripts (no names, no identifiable features) will be available to the above-named investigators for data analysis purposes. Electronic, de-identified data will be stored in a central encrypted server. The database will have firewalls to secure all information, and allow access by authorized, password-protected user accounts only. This will ensure all study participant information remains anonymous. Information from this study may be published or presented in public forums. Study findings will be reported in an aggregate form or summarized; however, we may use one of your direct quotes to illustrate a key point. Your name and other identifying information will never be used or revealed.

**Compensation**
As a token of our appreciation for your participation in the study, and as compensation for your time, you will be provided with a $25.00 gift card to Amazon.ca immediately upon completion of the interview.

**Voluntary Participation/Withdrawal from the Study**

Your decision to participate in this study is entirely voluntary. You are free to withdraw from the study at any time, and /or refrain from engaging without consequence. If you decide to withdraw after the interview, please contact Tara Horrill at [redacted] or [redacted] and specify the details of the comments that you would like to withdraw. We will either destroy the recorded interview if you completely want to withdraw your contribution; or if you wish to delete some comments from your interview, then we will review the transcript and delete the comments you want deleted. You will not be able to withdraw your data from the study after December 31, 2019.

**Debriefing**

During and following the interview, Tara Horrill will check-in with you to see how you are experiencing the interview. Following the interview, Tara Horrill will provide you with a brief summary of what you shared.

**Summary of Research Results & Dissemination of Research Findings**

The knowledge gained from this research will be shared with you before it is made public. You will receive a summary of the results by September 2020, by mail or email, whichever you prefer. The results will be presented at scientific conferences and published in a journal so that others learn from the research.

**Destruction of Confidential Data**

All personal information including names and consent forms will be kept secure in a locked cabinet at the Asper Clinical Research Institute for seven years. All hard copies and electronic copies of study documents will be destroyed according to the University of Manitoba's policy about destruction of confidential material, in February 2027.

**Questions**

You are free to ask any questions that you may have about your participation in this study and your rights as a research participant. If any questions come up during or after the study, you can contact Tara Horrill at [redacted] or [redacted]. Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

**The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.**

**This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca.**

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

Participant's printed name: _____

Participant's signature: _____

Date: _____

Researcher or Delegate's name: _____

Researcher or Delegate's signature: _____

Date: _____

**Check the correct box that corresponds to your wishes:**

☐ I wish to review the preliminary findings

☐ I wish to receive a summary of the project's findings

To review the preliminary findings and/or receive a summary of the project's findings, please provide your contact information below:

Mailing Address: _____

_____

OR

Email Address:

## Appendix N – Semi-Structured Interview Guide

**Demographic Questions:**

1. What type of nursing registration or licensure do you hold?
    a. RN
    b. LPN
    c. APN
    d. RPN
    e. Other _____

2. How many years have you been practicing as a nurse (total years in any nursing setting)?

3. How many years have you been practicing as an **oncology nurse**?

4. What is the highest level of professional education you have attained?
    a. Diploma
    b. Bachelor's degree
    c. Master's degree
    d. Doctoral degree

5. In what type of oncology setting do you practice?
    a. Provincial cancer center (CancerCare Manitoba; Saskatchewan Cancer Agency)
    b. Satellite cancer center (community cancer clinic)
    c. Community setting (palliative care)
    d. In-patient setting (hospital)

6. How often do you work with Indigenous patients in your oncology setting?
    a. Daily (at least once a day)
    b. Weekly (at least once a week)
    c. Monthly (at least once a month)
    d. Yearly (at least once a year)
    e. Never

7. What type of nursing position do you hold?
        a. Direct patient care
        b. Supervisory (clinical resource nurse, charge nurse)
        c. Managerial
        d. Executive

8. How do you identify your ancestry?

**Open-Ended Questions:**

9. Please tell me about a time when you cared for an Indigenous patient in your oncology nursing practice. What was that experience like for you? Was there anything that stood out for you?

10. Looking back at your nursing practice in oncology, can you think of a particular Indigenous patient that received quality care? If so, please describe that situation (no names) and explain how you determined that the care was "good". How would the patient have rated the provided care? Why?

11. Looking back at your nursing practice in oncology, can you think of a particular Indigenous patient where the care was perceived or was actually poor or substandard quality? If so, please describe that situation (no names) and explain how you determined that the care was "poor" or unsatisfactory. How would the patient have rated the provided care? Why?

12. Please tell me about a particular relationship with an Indigenous patient that was fulfilling or memorable. Tell me more.

13. What barriers do you think that Indigenous individuals face in accessing oncology care throughout their cancer journey?
    a. Probe: In your experience, are similar barriers faced by other Indigenous patients diagnosed with cancer?
    b. Probe: Are these different or similar from barriers to accessing care experienced by non-Indigenous patients?
    c. Probe: What is your understanding of Indigenous peoples' experiences with cancer screening? Diagnostic tests? Treatment decision-making? Treatments? Follow-ups?

14. From your perspective, what might improve access to oncology care for Indigenous patients?
    a. Probe: Tell me more about that.
    b. What role might nurses play?
    c. What (if anything) prevents you from implementing these strategies?

15. Is there anything else that you would like to add to what we have been discussing? Is there anything else that you would like us to know about your experiences caring for Indigenous peoples with cancer?