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Toward equitable access to oncology care for Indigenous Peoples in Canada: Implications for nursing

by Tara Horrill

ABSTRACT

As a result of overlapping social, economic, historical, and political influences, and intersecting experiences of racism, stigma and discrimination within healthcare, Indigenous Peoples in Canada experience inequitable access to healthcare and oncology care. The aim of this paper is to highlight some of the barriers contributing to inequitable access to oncology care, research examining oncology nurses' perspectives on these barriers and their roles in addressing barriers, and implications for nursing practice. Importantly, the role of nurses is not often considered in relation to healthcare access. By highlighting recent research evidence, I aim to open space to see the valuable work of oncology nurses, and to consider where and how we, as a profession, could better address inequities in access to oncology care for Indigenous Peoples.

Keywords: Indigenous Peoples, health services, healthcare accessibility, nursing, health equity, cultural safety, equity-oriented care

POSITION STATEMENT

I (the author) identify as a white, middle-class researcher and nurse. Although I bring experience working with Indigenous Peoples through clinical nursing practice and research, I do not speak for Indigenous Peoples. My work is informed by knowledge from the fields of oncology nursing, critical care nursing and community health, and literature authored by Indigenous and non-Indigenous scholars. I also draw on my experiences of witnessing inequities and injustices in healthcare, and through my work, seek to bear witness to such injustices, and aim to challenge others similarly positioned to do the same. I gratefully acknowledge that I live, play, work and raise my family on Treaty 1 territory, which are the original lands of the Anishinaabe, Cree, Oji-Cree, Dakota and Dene peoples, and the homeland of the Metis nation.

AUTHOR NOTES

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Inequitable access to healthcare is a significant issue among Indigenous Peoples[1], and evidence of systematic inequities in healthcare access are well documented, despite a publicly funded healthcare system with a commitment to provide universal healthcare access (Browne et al., 2011; Horrill et al., 2018; 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. In relation to oncology care, inequitable access among Indigenous Peoples is resulting in people who are not diagnosed in a timely way, who do not receive high-quality treatment or sometimes any treatment at all, and who do not receive the same supportive and follow-up care as others. As a profession with strong roots in social justice (Anderson et al., 2009; Thorne, 2014), these inequities ought to be of serious concern to nursing.

In this paper, I draw on a range of discussion papers and research evidence, including several studies from my doctoral dissertation, to highlight some of the barriers that are contributing to inequitable access to oncology care, oncology nurses' perspectives on these barriers and their roles in addressing barriers, and implications for nursing practice. Importantly, the role of nurses is not often considered in relation to healthcare access. However, my aim in this paper is to open space to see the valuable work being done by nurses, and to consider where and how we, as a profession, could better confront inequities in access to oncology care for Indigenous Peoples.

BACKGROUND

Health inequities can be understood as differences in health that are socially produced, unfair, and systematic in their distribution across a population (Commission on Social Determinants of Health, 2008). Health inequities are both created and maintained by social and structural determinants of health, or more simply, the circumstances and conditions in which we are born, grow up in, live, work, and age (Solar & Irwin, 2010). Social determinants of health include factors such as living and working conditions, income, social context, and healthcare access. Social determinants are shaped by structural forces, including public and social policy, economic contexts, social values, politics, and philosophies (Solar & Irwin, 2010). Indigenous Peoples in Canada are also significantly impacted by the social and

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. In this paper, I use the term Indigenous Peoples to refer to these groups.

structural forces of systemic racism and colonialism (Smylie & Firestone, 2016). One of the most egregious examples of the impacts of colonialism and systemic racism can be seen in the Indian Residential School systems, founded on racist ideas of Indigenous Peoples being inferior, which forcibly removed children from their homes, leading to loss of identity, loss of culture, and cumulative intergenerational trauma (Freeman, 2018; Smylie & Firestone, 2016).

These structural forces continue to have devastating and wide-ranging impacts on Indigenous Peoples' health and wellbeing. For example, Indigenous Peoples in Canada experience significant health inequities, including lower life expectancy, higher infant mortality rates, and higher rates of some chronic diseases (Public Health Agency of Canada, 2018; Smylie & Firestone, 2016). As an emerging chronic disease, cancer among Indigenous Peoples is particularly concerning. Trends in Canada show a rising incidence of some cancers among Indigenous Peoples which are stable or declining in the non-Indigenous population, patterns of diagnosis in which Indigenous Peoples are being diagnosed with advanced cancers that could have been detected through routine screening, and significantly worse mortality outcomes (Decker et al., 2016; Horrill et al., 2019a; Mazereeuw et al., 2018; McGahan et al., 2017; Sheppard et al., 2010; Withrow et al., 2017). Access to oncology care is particularly problematic for Indigenous Peoples, and a likely contributor to these concerning cancer disparities.

ACCESS TO ONCOLOGY CARE AMONG INDIGENOUS PEOPLES IN CANADA

Accessing oncology care is a complex process for many Indigenous Peoples, complicated by multiple intersecting and overlapping barriers (Horrill et al., 2022a). We know that the geographic location of many Indigenous communities, and the lack of healthcare providers and services locally can make cancer screening, diagnosis and follow-up challenging (Horrill et al., 2019b). We also know that transportation to and from appointments is a significant challenge, particularly when it is not convenient, reliable or affordable (Assembly of First Nations [AFN], 2009; Horrill et al., 2021; Maar et al., 2013). The sheer distance from Indigenous communities to specialized oncology care centres can be overwhelming – this often means several days away from work and family to attend appointments, and sometimes means that Indigenous patients are attending appointments or treatment cycles alone, and without the support of family (AFN, 2009; CancerCare Manitoba [CCMB], 2013; Horrill et al., 2021). Many oncology nurses will know from experience that the healthcare system broadly, and oncology care system specifically, can be fragmented, complex, and difficult to navigate for many individuals. This is especially true among for patients who are Indigenous, who must navigate additional layers of complexity related to policy and jurisdictional ambiguities. This has resulted in delayed cancer diagnoses, and some patients who decline treatment, or who choose to discontinue treatment (AFNations, 2009; Horrill et al., 2022a; Horrill et al., 2021; Lavoie et al., 2016). Importantly, design and delivery of oncology services, including inflexible appointment systems and long wait times, can further complicate access issues (Howard et al., 2014; Macdonald et al., 2015; The Saint Elizabeth First Nations Inuit and Metis Program, 2012; Zehbe et al., 2017).

The delivery of healthcare services at the point of care, and the interactions between healthcare providers and patients are also fundamental (yet often overlooked) components of healthcare access that are especially important in the context of Indigenous Peoples (Horrill et al., 2020a; Horrill et al., 2018; Tang et al., 2015). Personal experiences of trauma and abuse, histories of residential school attendance, and the lack of understanding among healthcare providers of the impacts of these experiences creates significant barriers to accessing oncology care across the cancer continuum for Indigenous peoples (AFN, 2009; Black, 2009; CCMB, 2013; Minore et al., 2004). Research suggests that many Indigenous Peoples have negative experiences when accessing oncology services, including having concerns dismissed or not taken seriously by providers, being labelled or judged, or experiencing overt racism (Horrill et al., 2022a; Horrill et al., 2021). Lack of culturally safe care that is grounded in relationship, trust, and reciprocity, is a major barrier to accessing oncology care (AFN, 2009; Black, 2009; CCMB, 2013; Hammond et al., 2017; Horrill et al., 2022a). Rooted in systemic racism and colonialism, socioeconomic conditions, including poverty, food insecurity, and lack of stable and affordable housing, magnify existing barriers to accessing oncology care for many Indigenous Peoples (AFN, 2009; Black, 2009; Horrill et al., 2021; Saint Elizabeth, 2012).

ONCOLOGY NURSES AND ACCESS TO CARE

Nurses are the largest body of healthcare providers in Canada and play key roles in delivering care across the cancer continuum. Given our understanding of the impacts of nurse-patient interactions, and the holistic focus of nursing practice, oncology nurses could play a significant role in addressing issues of inequitable access to care among Indigenous Peoples. As part of my research, I have sought to understand the role of oncology nurses in facilitating access to care. Findings from surveys and interviews with oncology nurses across Canada suggest that many of them see themselves as mediators of access to oncology care: they are active in the process of helping Indigenous patients gain access to care. In many cases, oncology nurses are 'coordinators' of care, working on behalf of patients to bridge gaps and ensure seamless care (Horrill et al., 2021). This may include, for example, liaising with community care settings (e.g., nursing stations, primary care providers) to ensure patients are receiving necessary care close to home, and that community providers are up to date on patients' care needs. Many oncology nurses help to guide patients in navigating the oncology care system by troubleshooting barriers and connecting them to resources, and this is not unique

to those in dedicated oncology nurse navigator roles (Horrill et al., 2021). Oncology nurses also see themselves as advocates, advocating for patients and families to gain access to care, and less often, advocating for policy and/or system change (Horrill et al., 2021). Some oncology nurses have also highlighted the need to focus on relational aspects of care to improve access. Building trust and reciprocity within the context of nurse-patient relationships is particularly important given the historical and current context of interpersonal and systemic racism towards Indigenous Peoples, personal and collective trauma resulting from colonial government policies, and a distrust of government institutions, including healthcare institutions.

However, despite the important roles that oncology nurses play in facilitating access to care among Indigenous Peoples, the impacts of social and structural determinants of health, systemic racism, and the lack of culturally safe care on access to oncology care are not always well understood by oncology nurses (Horrill et al., 2019b; Horrill et al., 2021). In my research, racism was often discussed in terms of interpersonal racism (e.g., negative encounters with healthcare providers) with little acknowledgement of how systemic racism operates to limit access to care and other social determinants of health (Horrill et al., 2021). In line with these findings, access to oncology care tends to be understood by healthcare providers at the level of the individual patient, with less attention to the impacts of and ways to mitigate structural and health systems-level barriers to accessing care (Horrill et al., 2019b, 2021). And although oncology nurses saw themselves as advocates, their advocacy often did not extend beyond individual patient challenges (Horrill et al., 2021). This may be related to how nurses are trained to primarily "see" and address problems of individual patients, and because many of the solutions to addressing systemic and structural barriers lie beyond the scope of nurses' practice with individuals. At the same time, oncology nurses described how they felt constrained in their practice. Fast-paced clinical environments, high patient loads, and lack of input into larger policy and decision-making systems made it difficult for oncology nurses to provide care beyond the essential (Horrill et al., 2021, 2022a). Although some oncology nurses did recognize and navigate social and structural barriers to care, they also recognized that they alone did not have the capacity to redress those barriers (Horrill et al., 2022a).

IMPLICATIONS FOR NURSING

What implications do these research findings have for nursing, and for oncology nurses specifically? How can we work to ensure equitable access to care for Indigenous Peoples, and other groups impacted by inequities?

What is urgently needed to address persistent health inequities, in line with nursing's social justice roots, is a shift in focus towards the structural conditions that determine health and healthcare access (Pauly et al., 2009). This refocusing could be fostered by attention to nursing practice and practice contexts, advocacy at the policy level, and changes in nursing education. In the discussion that follows, I highlight several key implications for growth and development in each of these areas.

Implications for Nursing Education

Nursing education could play a significant role in addressing the need within the profession, broadly 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 tends to be 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). Issues of social justice, racism, power, and privilege have historically been entirely absent or only briefly covered in undergraduate nursing education (Bell, 2020; Blanchet Garneau, et al., 2018; van Herk et al., 2011). Moreover, continuing education in oncology nursing is often focused on understanding treatment advances, pathophysiology, or aspects of care for narrowly defined patient groups, and rarely includes a broader focus on social or structural issues.

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 focus on structural determinants of health (Metzl & Hansen, 2014). 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, should be an essential component of basic and continuing nursing education (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. Critical to moving forward as a profession are nurses who recognize and challenge racism in nursing practice, which requires nursing education (both undergraduate and continuing education) that explicitly addresses issues of power, privilege, and 'race' (Scammell & Olumide, 2012). Fostering capacity to recognize and address racism, 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.

Implications for Nursing Advocacy

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 health policy and other 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). 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, Hooker, & Davey, 2009; Lambert et al., 2021; Sayani, 2019). This represents a significant opportunity for oncology nurses and oncology nursing organizations such as CANO/ACIO to advocate for policy change.

Expectations that nurses advocate for social justice are threaded throughout nursing guidelines, standards of practice and codes of ethics, including the Canadian Nurses Association's (CNA) code of ethics (CNA, 2017). 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 (Falk-Rafael & Betker, 2012). As nurses, we have first-hand knowledge of the challenges faced by our patients, making us 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, Reutter, & Allen, 2006; Thorne, 2014; Weitzel et al., 2020). This collective 'power in numbers' speaks to the importance of professional nursing organizations like the CNA and CANO/ACIO, which have the existing infrastructure and relationships to support policy advocacy collectively.

Implications for Nursing Practice

Lack of culturally safe care is a significant barrier to accessing oncology care for Indigenous Peoples in Canada (Horrill et al., 2019b, 2020b, 2022a). Moreover, there is strong evidence regarding the devastating impacts of racism and discrimination on healthcare accessibility and experiences of care among Indigenous Peoples (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). A key pathway to addressing inequities in access to oncology care includes integrating approaches into the design and delivery of oncology care that purposefully attend to these barriers.

Equity-oriented healthcare (EOHC) is an approach to improving care that focuses on reducing the impacts of structural inequities such as poverty and racism, and the persistent mismatches between current approaches to healthcare and the actual needs of people, by informing organizational-level changes in how services are designed and delivered (Browne et al., 2018, 2016; Horrill, Browne, & Stajduhar, 2022b). Browne et al. have articulated a transformative approach to equity-oriented healthcare founded on three key dimensions: (1) trauma- and violence-informed care, (2) culturally safe/anti-racist care, and (3) harm reduction philosophies with attention to mitigating substance use stigma. Importantly, equity-oriented healthcare is tailorable to diverse groups because of the explicit focus on counteracting racism and stigma, building trust, fostering safety, and creating a welcoming environment for people who often do not feel welcomed in healthcare settings. These key dimensions can be used in guiding individual nursing practice, evaluating and re-designing oncology nursing services, implementing organizational interventions, and developing policies and strategic plans (Wathen & Varcoe, 2022).

While equity-oriented care approaches hold promise for addressing racism, mitigating culturally unsafe care, and drawing attention to structural determinants of health, the integration of these models of care into clinical practice must be done critically and thoughtfully. My research with oncology nurses demonstrated that their attempts at delivering culturally safe and trauma-informed care was constrained at times by the organizations and systems in which they worked (Horrill et al., 2022a). Indeed, the integration of equity-oriented healthcare models is highly dependent on the sociopolitical and organizational context, and shifts at the organizational level are required to re-orient services towards equity (Ford-Gilboe et al., 2018; Lavoie et al., 2018; Levine et al., 2020). 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 equity-oriented healthcare, including the integration of culturally safe and anti-racist approaches, trauma- and violence-informed care, and attention to philosophies of harm reduction (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 issues of access to care and respond to the unique needs of Indigenous Peoples by building alliances with community organizations (Baum et al., 2013; Yaphe, Richer, & Martin, 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 trauma- and violence-informed care; consideration of models that better support equity-oriented care is warranted (Lavoie et al., 2018; Levine et al., 2020).

CONCLUSION

Action to address the inequities in access to oncology care among Indigenous Peoples in Canada is urgently needed. In this paper, I have highlighted some of the barriers contributing to inequitable access to oncology care, the roles and work of oncology nurses to address gaps in care, and implications for nursing practice. As oncology nurses, we have essential roles to play and important contributions to make in addressing inequities in access to care. While improving access to oncology care alone will not ameliorate cancer disparities among Indigenous Peoples, it is a step in the direction of equity and towards justice.

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

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