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Building bridges between clinic and community: Supporting patients and caregivers living in rural and remote Canada

by Reanne Booker

ABSTRACT

Advances in the detection, diagnosis, and treatment of cancer have paralleled significant developments in the understanding of tumour biology, pathophysiology, and genomics. In spite of this, cancer remains the lead- ing cause of death in Canada, with an estimated two in five Canadians expected to be diagnosed with cancer and one in four Canadians expected to die of cancer in their lifetime. Although Canada has a pub- licly funded, universal healthcare system, profound inequities exist across the country. Such inequities are often due to a multitude of intersecting factors. The focus of this paper is to review the impact of rurality on cancer care. People residing in rural and remote regions are known to have reduced access to and availability of cancer care, from prevention through diagnosis, treatment, follow-up, and palliative care. Potential strategies to mitigate the challenges associated with rurality will be discussed, including an overview of the role that nurses can play in addressing the needs of patients in rural regions. Oncology nurses are well suited to help support patients, their loved ones, and healthcare colleagues in rural settings with a view to helping improve equity in access to care, quality of care, and outcomes of care for all Canadians.

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BACKGROUND

In spite of incredible advances in cancer care over the past few decades, cancer continues to be a leading cause of death in Canada (Brenner et al., 2022). While healthcare in Canada is publicly funded and intended to be universally accessible, it is known that innumerable inequities exist throughout the cancer care trajectory, from prevention through diagnosis, treatment, follow-up, and palliative and end-of-life care (Lambert et al., 2023). Such inequities, often the result of overlapping factors such socioeconomic status, race, level of education, and rurality, may lead to disparate outcomes in cancer care, including survival (Coughlin, 2021; Lambert et al., 2023). This paper will focus on the challenges faced by patients with cancer who reside in rural and remote regions of Canada.

With just under 10 million square kilometers, Canada is the second largest country, by area, in the world (Statistics Canada, 2018). By population, however, Canada does not even make the top 10 most populated countries in the world, with approximately four people per square kilometre, compared to India, with 481 people per square kilometre (World Population Review, 2023). The vast majority of Canadians live within proximity of large urban centres, with only a small share of the total population residing in rural areas (Statistics Canada, 2022). To illustrate, while Canada's three territories make up nearly 40% of the country's landmass, only 0.3% of Canadians live in the territories (Statistics Canada, 2022). During the coronavirus disease-2019 (COVID-19) pandemic, in part due to the increase in telework, there was a rise in Canada's rural population by approximately 0.4% with the rural population increasing to just over 6.6 million in 2021 (Statistics Canada, 2022).

There are varying definitions of what constitutes rural and remote areas. For this paper, the definitions used by Statistics Canada will be used.

- **Urban** – census metropolitan areas (CMAs) and census agglomerations (CAs) with a core population of 10,000 or more; 50% or more of the population commutes to CMA/CA
- **Rural** – population of less than 10,000 and 30–49% of the population commutes to an urban area
- **Rural-Remote** – population of less than 10,000 and 5–29% of the population commutes to an urban area
- **Rural/Very Remote** – populations of less than 10,000 and 0–5% of the population commutes to an urban area; includes non-urban parts of the territories

Health of Rural and Remote Canadians

Subedi et al. (2019) conducted analyses, using Canadian Vital Statistics Death Database from 2011 to 2015 and the 2016 Census of Population, to describe the geographic variability of preventable and treatable mortality rates across Canada. The results revealed significant variation in both preventable and treatable mortality rates by relative remoteness of Canadian communities with both being higher in more remote areas compared to easily accessible areas (Subedi et al., 2019). The authors surmised that the higher mortality rates in remote areas could be due to

geographic barriers, limited healthcare services, and unmet healthcare needs, as well as historical and environmental factors that influence the socioeconomic status of people residing in rural communities (Subedi et al., 2019).

Specific to cancer care outcomes, Carriere et al. (2018) conducted a meta-analysis to examine the global literature on rural cancer survival. Of the 39 studies included in the review, the authors found that rural dwellers with cancer were 5% less likely to survive cancer than urban dwellers (HR 1.05, 95% CI 1.02–1.07). The adverse impact on survival was maintained across studies and using various definitions of rurality. Similarly, Afshar et al. (2019) conducted a systematic review to examine the association of place of residence (rural versus urban) and cancer survival in high-income countries. The review included 45 studies, four of which were Canadian, that had been published between 1984 and 2016. The majority of the studies reported worse survival for patients who lived in rural settings compared to those in urban settings (Afshar et al., 2019).

The Canadian Cancer Society (CCS) published a special report in 2022 that highlighted differences in cancer prevalence among those living rurally. When all cancers were combined, the crude two-year, person-based prevalence proportion was higher for people living in rural areas (944.5 per 100,000) compared to those living in urban areas (805.9 per 100,000) (CCS, 2022). Differences in mortality due to cancer have also been reported. For example, data published in 2021 showed that Nunavut had an age standardized mortality rate (ASRM) of 224.5 per 100,000 compared with an ASMR of 177.6 per 100,000 in Ontario (CCS, 2022).

There are a number of potential reasons for discrepancies in mortality between rural and urban patients (Frosch, 2022). Rural patients may have reduced access to screening and, thus, may be diagnosed with later stage disease, which can impact curability (Hanna et al., 2020; Yabroff et al., 2020). In addition, the travel required to attend systemic or radiation therapy appointments may deter patients from undergoing or completing such treatment (Egilsdóttir et al., 2022; Lin et al., 2015).

Reasons for Disparities in Cancer Outcomes

In relation to cancer care, differences in cancer-related outcomes for rural and non-rural patients may arise from an array of factors, including sociodemographic factors, as well as factors related to healthcare system inequities (Bhatia et al., 2022). These will be explored in more detail below.

Sociodemographic Factors

Rural patients often encounter a variety of sociodemographic factors that can influence cancer outcomes. Rural patients are typically older and have poorer general health, with more comorbidities than their urban counterparts (Garcia et al., 2017; Henley & Jemal, 2018, Levit et al., 2020). In addition, rural patients have been found to have higher rates of obesity, disability, and cigarette smoking (Henley et al., 2017; Zahnd et al. 2018). Further, rural residents have been found to have lower access to prevention and screening services and accordingly, higher rates of cancers associated with modifiable risk factors, such as tobacco-associated and human papillomavirus-associated cancers (Henley & Jemal, 2020; Zahnd et al., 2018).

Previous research has identified socioeconomic status as a powerful predictor of health status, morbidity, and mortality (Mitra et al., 2015). Income tends to be lower and unemployment levels tend to be higher in rural regions compared to those in urban settings (Infrastructure Canada, 2022). Education level attainment and literacy, including health literacy, have also been found to be lower in rural areas compared to urban areas (Brunello et al., 2016; Rural Health Information Hub, 2022). Notably, cultural trust in the medical system can also impact health outcomes. Systemic racism and structural violence continue to pervade healthcare in Canada and the consequences have proved deadly (MacLean et al., 2023). Intergenerational trauma and ongoing settler colonialism can perpetuate mistrust and unease for rural Indigenous patients in Canada (Burnett et al., 2020; Schill & Caxaj, 2019).

Healthcare Services

People in rural areas face more difficulty accessing healthcare than their urban counterparts. While almost one-fifth of Canadians live in rural communities, they are served by only 8% of the physicians (N=93,998) practising in Canada (Canadian Institute for Health Information, 2023; Wilson et al., 2020). Rural communities face ongoing challenges in recruiting and retaining family physicians and other healthcare professionals. Disparities in access are even more pronounced when considering specialty oncologic care.

Specialty Oncologic Care. Most rural hospitals and oncologists are unable to offer the same multidisciplinary services or levels of expertise as urban centres (Levit et al., 2020; Pfister et al., 2015). This means that rural patients do not have the same access to the types of diagnostics, treatment, and supportive care services in their communities that are available in urban centres (Bhatia et al., 2022). Mortality rates tend to be lower at specialized cancer cen- tres when compared to community hospitals for some types of cancer (Pfister et al., 2015; Shulman et al., 2018). While the precise reasons for discrepant survival rates have not been identified, differences may be due to lack of specialized pathology and radiology services in community hospitals that can be instrumental in diagnosing cancer and monitoring responses to treatment (Nass et al., 2018).

In Canada, only approximately 2% of specialists practise in rural areas (Canadian Medical Association [CMA], 2019a). As of 2019, the number of radiation oncologists varied between none in the territories (0/100,000 population) to 238 in Ontario (1.6/100,000) (CMA, 2019b). Similarly, as of 2019, there were no medical oncologists in the terri- tories (0/100,000) and 236 in Ontario (1.6/100,000) (CMA, 2019c). It is difficult to estimate the number of specialized cancer nurses working in Canada. Of the 439,975 regulated nurses in Canada in 2019, only 39,502 or 8.98% work in rural areas, with the majority being Registered Nurses (n = 24,997) followed by licensed practical nurses (n = 12,826) (Canadian

Association for Rural & Remote Nursing, 2020). In contrast, 355,724 or 80.9% of regulated nurses work in urban areas. Whereas specialty oncology nurses possess precise cancer nursing expertise and skills, rural nursing practice is typically complex and generalist in nature (MacLeod et al., 2019). Accordingly, rural nurses require an extensive and diverse range of knowledge and skills (MacLeod et al., 2019).

Clinical Trials. Clinical trials are essential in advancing the field of cancer care. The discovery of new and potentially better approaches to prevent, diagnose, treat, and support people with cancer is contingent upon findings derived from clinical trials (Unger et al., 2016). In addition to advancing cancer care, clinical trials may be beneficial to the patients participating in them. Some patients participate in clinical trials for altruistic reasons, hoping to help future patients and society (Ulrich et al., 2022). For some patients, such altruism can impart meaning to the cancer experi- ence. Further, clinical trials may convey a sense of hope and, additionally, may offer new or innovative treatment options for patients when other disease-directed treatments have been exhausted (Ulrich et al., 2022).

Participation in cancer clinical trials is low in Canada, with reported rates of trial participants to new incident cancer cases of 4.7% overall and as low as 1% in some Canadian provinces (Sundquist et al., 2021). Low rates of participation may be attributable to access to some degree, but may also be due to the fact that rural patients are often sicker, with more comorbidities and, thus, not eligi- ble to participate (Levit et al., 2020). The ability to attend multiple visits required for clinical trials, and associated travel and time away from home, may also preclude participation (Sundquist et al., 2021).

Importantly, a comparative effectiveness retrospective cohort analysis involving 36,995 patients from across the United States from January 1986 to December 2012 found that when rural and urban patients had uniform access to cancer care through participation in a Southwest Oncology Group clinical trial, they had similar outcomes. The findings indicate that improving access to uniform treatment options may help diminish disparities in cancer out- comes between urban and rural patients (Unger et al., 2018).

Transportation Barriers

Barriers related to transportation have been found to impact all aspects of the cancer care trajectory from diagnosis, through treatment and disease-related follow-up care (Graboyes et al, 2022). Timeliness of care may therefore be affected, where patients facing transportation barriers can experience delays in confirmatory testing and diagnosis, as well as in initiation of treatment (Wercholuk et al., 2022). Further, patients who experience transportation barriers may have difficulty adhering to treatment schedules, may forego, miss, or delay treatment, or may terminate treatment early, all of which may adversely impact treatment outcomes, including survival (Graboyes et al., 2022). Missed clinic appointments can reduce the ability to pick up on signs and symptoms of disease progression or recurrence and lead to suboptimal outcomes (Delgado Guay et al., 2014; Ohri et al., 2016).

Mitigating the Challenges Faced by Rural and Remote Communities

While it has been established that patients who reside in rural and remote communities confront a multitude of factors that can impact cancer care and outcomes, there are innumerable opportunities to help mitigate barriers to care and improve outcomes.

Cancer Care Infrastructure

Bringing Services to Patients. Strategies to reduce disparities between rural and urban patients should be implemented even before a cancer diagnosis is made. Educating the general public on signs and symptoms of cancer, modifiable risk factors such as diet, exercise, and decreased alcohol consumption, and the importance of screening and early detection are imperative. Improved access to screening via mobile services, such mobile mammography and prostate-specific antigen testing, can help reduce the burden associated with travel to and from screening centres (Walji et al., 2021).

An additional potential approach to address challenges associated with transportation includes the use of ride-sharing programs, such as Uber or Lyft, hospital-based transportation programs, and partnering with community organizations that assist with transportation, such as the Canadian Cancer Society volunteer driver program (CCS, 2023). However, these resources may be scarce or may not exist at all in rural and remote regions.

Outreach clinics, where specialists travel to rural communities, eliminate the need for patients to travel for care. Such clinics can be set up to provide specialized cancer care to rural communities via telemedicine, or by having a specialist visit rural communities (Gruca et al., 2014). A potential downside of the outreach clinic approach is that patients typically do not have access to the various multidisciplinary providers and services that are available in specialized cancer centres (Levit et al., 2020).

Primary care providers, including nurse practitioners (NPs), often support cancer care in rural and remote communities (Tremblay et al., 2016). In addition to advanced clinical skills, such as diagnosing illness, ordering and interpreting tests, and managing treatment, including prescribing medications, NPs also are also proficient in research, education, and leadership (Wilson et al., 2021). NPs work both autonomously and collaboratively and can help address gaps in care, including issues pertaining to access and equity. As of 2021, there are more than 7,400 NPs practicing in Canada (CIHI), the majority of which work in urban settings. However, the Northwest Territories and Nunavut have the highest number of NPs per 100,000 population at 72, compared with only 11 NPs per 100,000 population in Quebec (CIHI, 2022).

Oncology nurse navigators have been increasingly incorporated into care teams to help overcome barriers to decrease disparities and improve access to care (Chan et al., 2023). Nurse navigators have been utilized to help underserved groups address access barriers, such as transportation and financial barriers. Key components of

nurse navigation include care coordination, education/information provision, empowerment, comfort/emotional support, care provision (such as symptom management), advocacy, language, and financial assistance (Chan et al., 2023). Rural oncology nurse navigators could help connect patients with local resources, including transportation resources. However, this approach relies on the need for tangible resources to which patients can be referred in the first place (Wercholuk et al., 2022).

Innovations in Cancer Care Delivery. As with outreach clinics, reducing the need to travel to and from the cancer centre for appointments, including treatment appointments, is another potential strategy to assist rural patients. In the context of the COVID-19 pandemic, many cancer centres shifted to virtual delivery of cancer care (Booker & Haase, 2022). There are numerous benefits associated with virtual cancer care, including decreased costs associated with travel and accommodation. However, virtual appointments must be weighed against the potential risks associated with less-frequent, in-person assessments. In addition, virtual appointments may not be suitable for all types of appointments or for all patients. Without careful consideration to factors such as availability of internet access and devices, existing inequities could be exacerbated.

An additional approach that could help ease the burden associated with travel to and from cancer centres is that of home delivery of cancer treatment. Chini et al. (2021) explored the feasibility of home delivery of chemotherapy for patients with advanced disease who had limitations to day-hospital access, comorbidities, and who were expected to need treatment for six months or more. The study involved 188 patients who received cancer treatments, including oral, subcutaneous, and intravenous treatments, and supportive care, such as blood transfusions, in their homes (Chini et al., 2021). The authors found that home administration of cancer treatments was feasible and safe, and patients' satisfaction with home treatment was high (Chini et al., 2021).

Where reasonable, modifying the route of administration of anti-cancer agents from intravenous to subcutaneous (SC), such as with bortezomib, azacitidine, trastuzumab, and rituximab, may allow for administration by patients or family members, reducing the need for travel (Boudreau, 2019; Leveque, 2014). However, comprehensive patient education and counseling must be provided in advance of changing from intravenous (IV) to SC delivery, including how to safely administer the medication, as well as how to monitor for, report, and manage any adverse reactions (Boudreau, 2019). Similar to SC administration, the use of oral anti-cancer agents may also reduce the travel requirements associated with IV treatment. In their review of the literature on patient-reported preferences for oral versus IV cancer treatment, Eek et al. (2016) found that patients preferred oral treatment because of convenience (including the ability to take the med- ication at home and the associated reduced need to travel), perception of efficacy, and past experience. Of note, patients were typically not willing to accept reduced efficacy or greater treatment toxicity in favour of other oral treatment benefits, such as convenience (Eek et al., 2016).

Approximately half of all patients with cancer receive radiotherapy (RT) at some point during their treatment trajectory (Cothran & Martin, 2022; Thompson et al., 2018). In Canada, radiotherapy is only provided at cancer centres that are located in urban settings. As of 2018, there were 44 cancer centres providing RT, 14 of which were in Ontario alone (Guiliani & Gospodarowicz, 2018). Where possible, minimizing the number of trips required for RT, which can be achieved via hypofractionation, where treatment is delivered in fewer doses, has been suggested to reduce the burden imposed by travel (Cothran & Martin, 2022; Kenamond et al., 2022).

Clinical Trials. Clinical trial participation by rural patients is known to be low (Sundquist et al., 2021), with distance from the clinical trial site being a major barrier. Making trials more available to rural patients may expand treatment options for these individuals. Decentralizing clinical trials, where some activities are performed at non-trial sites and even in patients' homes, has been suggested as a strategy to improve clinical trial participation, particularly for patients in rural and remote regions (Chen et al., 2022). Other suggestions include the use of telemedicine for virtual consults, direct-to-patient shipping of oral study drugs, and the use of local laboratories and diagnostic imaging services. Reducing the travel requirement for trial participants is associated with reduced costs associated with travel, reduced need to take time away from work, and improved access for patients with mobility issues (Chen et al., 2022). Digital health technologies could assist with participant recruitment, engagement, therapeutic interventions, and data collection (such as with the use of digital patient-reported outcome measures). Further, wearable biometric devices are increasingly being utilized for monitoring various outcomes during trial participation (Chen et al., 2022).

Reducing the Financial Burden of Residing Rurally/Remotely

Patients bear significant financial burdens associated with travel to/from cancer care, including costs for gas, train/bus/airline tickets, and accommodations and meals while away from home (deMoor et al., 2022). In addition, they also encounter costs associated with travel such as those related to childcare and time away from work. Kornelsen et al. (2021) conducted an online retrospective, cross-sectional survey to estimate the out-of-pocket (OOP) costs and personal experiences of rural patients associated with traveling to access healthcare in British Columbia. Respondents were surveyed across five categories: Distance Traveled and Transportation Costs, Accommodation Costs, Co-Traveler Costs, Lost Wages, and Patient Stress. On average, costs for respondents were $856 and $674 for transport and accommodation, respectively. Out-of-pocket costs increased with distance travelled with the average OOPs being $112, $473, $682, $1,731

for distances up to 200km, 712km, 3,636 km, and 22,990 km respectively (Kornelson et al. 2021).

Financial supports for patients and caregivers may be available, but even where they are available, many individuals may not be aware of them or may require assistance to obtain such supports (Longo et al., 2021).

Education and Supports for Clinicians in Rural/Remote Region

Supporting primary care providers and other local clinicians to provide community cancer care is another potential strategy to help rural patients with cancer. One example of an innovative educational model that facilitates continuing education and professional development for rural providers is Project Extension for Community Healthcare Outcomes (Project ECHO) (Arora & Byers, 2020). The ECHO model involves interdisciplinary teams of experts, typically based at tertiary medical centres, or 'hubs', that mentor and support rural providers who participate remotely via videoconferencing. Anonymized patient cases are discussed, allowing for treatment recom- mendations to be made by the experts and creating a virtual community of practice (Arora & Byers, 2020). The ECHO model has been used to support care throughout the cancer continuum, from prevention and screening to palli- ative care. Project ECHO was developed in 2003 by Dr. Sanjeev Arora (Lopez et al., 2017).

The Canadian Association of Nurses in Oncology offers educational resources, including webinars and best practice documents, for specialized oncology nurses, as well nurses who may not be specialized in cancer care but who provide care to patients with cancer, irrespective of the practice setting (Nowell & Campbell, 2020).

The pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) is an initiative developed by Canadian oncology nurses that includes 17 practice guides that cover some of the most common symptoms that patients with cancer encounter (Stacey et al., 2023). The practice guides are publicly in English and French (https://ktcanada.ohri.ca/costars; https://www.canoacio.ca/page/telephone_guidelines). COSTaRS practice guides provide evidence-informed information for nurses and other healthcare professionals to support the provision of safe, consistent cancer symptom management (Stacey et al. 2020).

CONCLUSION

People diagnosed with cancer who reside rurally and remotely in Canada face a wide array of challenges that can adversely impact disease and treatment-related outcomes, including survival. Access to and availability of cancer care services, transportation barriers, as well as sociodemographic factors can all contribute to disparate outcomes for patients in rural and remote regions. Inequities exist throughout the cancer care trajectory, from prevention and screening, through diagnosis, treatment, follow-up, sur- vivorship, and palliative care. Lack of access to multidisciplinary services and resources, including lack of supports for family members and loved ones, can lead to diminished quality of life and lower overall survival for people with cancer. Nurses play an integral role in helping to bridge the gap between specialty cancer centres and community. In particular, their roles as navigators, clinicians, educators, and researchers will help ensure that all Canadians have access to timely, comprehensive, equitable care, irrespective of place of residence.

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