“In a good way”: Going beyond Patient Navigation to ensure culturally safe care in the cancer system for First Nations, Inuit, Métis, and urban Indigenous patients in Ontario

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Abstract

Background: Many Indigenous peoples use the medicine wheel as a holistic model to depict how all elements of life are inter-connected. It is only recently that some Western systems are making space for incorporating these Indigenous ways. The Indigenous Navigator role, within Cancer Care Ontario (CCO), models such a method. Methods: A literature review was conducted to investigate the scope and responsibilities of the Navigator role in cancer systems outside of Ontario. Then, annual activity reports (2016/2017) submitted by the CCO Indigenous Navigators were reviewed and synthesized to assess areas of strengths and challenges of the role and to describe the scope of the role in Ontario. Results: The Indigenous Navigators in Ontario exceed the scope of the role described in the literature. Engagements with cancer patients, their families and communities are summarized using the quadrants of a medicine wheel (which includes physical, mental, spiritual and emotional wellness). Examples of the extent of the role include facilitating traditional healing, providing health literacy assistance, alleviating anxiety, and getting patients to the right support at the right time. Conclusions: Navigating the cancer system can be a significant challenge for First Nations, Inuit, Métis and urban Indigenous (FNIMuI) patients. CCO’s Indigenous Navigators provide support and advocacy for FNIMuI patients and families by facilitating and coordinating access to cancer services for palliative and supportive care, addressing cultural and spiritual needs, and networking with FNIMuI and non-Indigenous partners to make the cancer journey a culturally safe experience for FNIMuI patients and families. We recommend other cancer agencies and health entitles at large implement this or a similar approach towards improving the physical, mental, spiritual, and emotional wellbeing for the Indigenous peoples they support.

Keywords

Navigator, cancer care, First Nations, Inuit, and Métis

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Glossary

CCO Cancer Care Ontario
FNIMuI First Nations, Inuit, Métis and urban Indigenous
ICCU Indigenous Cancer Care Unit
RCP Regional Cancer Program

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Introduction

“I take direction from patients and do my best to help them with whatever they need for their life journey.” (Beaver, 2018; p. 1)

Access to quality and culturally relevant health care that serves an individual’s many health needs is a pillar of Canada’s healthcare system. A positive encounter in the healthcare system is not only important for the early diagnosis and treatment of chronic and acute medical conditions, but the point-of-contact with healthcare providers is formidable as it sets the tone for the overall experience. Nonetheless, First Nations, Inuit, Métis and urban Indigenous (FNIMuI) peoples are more likely to have health professionals not listening or addressing their needs, thus generating a lack of trust in the medical system (Jull, 2017); experience fragmented care due to jurisdictional issues, and more barriers in coordinating care (Lavoie et al., 2016). Additionally, the legacy and contemporary impacts of colonialism translates to First Nations, Inuit and Métis peoples experiencing a lack of adequate, equitable and culturally appropriate health care services.

The First Nations Regional Health Survey (RHS) is the only First Nations governed national health survey in Canada. It collects information about on reserve and northern First Nations communities based on both Western and traditional understandings of health and wellbeing. Findings from the RHS indicate the following: that the perceived quality of care in remote First Nations communities is lower than in rural and urban communities. The main barriers to receiving health care in First Nations communities are long wait times and a lack of doctors and nurses. Nearly 1 in 10 First
Nations adults that required health care in the previous twelve months did not receive all the care they needed (FNIGC, 2018). Moreover, 27.27% (19.05-35.49 95% C.I.) of a respondent-driven sample of the Nations, Inuit and Metis populations in Toronto, the largest urban centre in Ontario, self-reported unmet health needs in the healthcare system (Kitching, 2017).

According to the 2016 Canadian Census, there are approximately 375,000 people with Indigenous identity in Ontario, including over 236,000 First Nations, 120,000 Métis, and 3,800 Inuit (Statistics Canada, 2016). However, according to Smylie and Firestone (2015) the Census values underestimate the true size of these populations. Knowing who and where people are is vital to curating relevant health services. Furthermore, there are barriers to accessing health services in hard to reach communities, but also in centres that are geographically closer to the mainstream health system. We know that geography is only but one determinant of health, and in fact health outcomes are a result of a complex set of influences (Greenwood et al., 2018). For example, the impact of colonization includes generations of attempts at marginalization and cultural genocide, leading to poverty, underemployment, and overcrowding and ultimately poorer health status. While many FNIMuI communities and peoples are thriving, a high proportion of these populations experience negative health and health system consequences (TRC, 2015). For example, according to Logan (2017, p.1), “First Nations families are less likely to have a family physician, have a health card, have transportation to appointments, nor have access to transportation.”

In general, cancer rates in Ontario are rising quicker for First Nations people overall, when compared to others in the province. For example, from 1991 to 2010, colorectal cancer incidence increased by 7% among First Nations men, whereas rates stayed the same in other men in Ontario. Furthermore, rates of colorectal cancer increased by almost 6% during the same period for First Nations women, while rates decreased among other women in the province (COO et al., 2017). Cancers are diagnosed at later stages, and survival for major cancers is significantly worse (Sheppard et al., 2010; Sheppard et al., 2011). “Patients and families are still struggling in silence” (Logan, 2017, p.1). A complete picture of the cancer burden for FNIMuI is not known due to data limitations described elsewhere (COO et al., 2017).

Methods

Navigating the complex cancer system

The “overwhelming recommendation coming from the patients, the survivors and their families was that the system was extremely complex and they needed assistance in just transitioning through the maze.” (Walkinshaw, 2011, pp. E1109-10)
A literature review was conducted to investigate the scope and responsibilities of the Navigator role in cancer systems outside of Ontario. Then, annual activity reports (2016/2017) submitted by the CCO Indigenous Navigators were reviewed and synthesized to assess areas of strengths and challenges of the role and to describe the scope of the role in Ontario.

Patient navigation is an intervention that helps patients overcome barriers to care through culturally competent, sensitive and appropriate coordination of care and support. The concept is largely attributed to Dr. Harold Freeman, who first developed the model to reduce disparities in breast cancer care borne by the low-income African-American and Latino population he served in Harlem, New York City in 1990 (Hopkins and Mumber, 2009). The program was able to demonstrate a reduction in racial, ethnic, and poverty-driven disparities in care as a result of employing, what were called, Patient Navigators who were from the community or who were culturally similar to the population served (Vargas et al, 2008). Dr. Freeman’s model was quickly recognized for its success and more patient navigation programs have since been implemented globally to assist patients and their families in navigating cancer systems and are increasingly becoming the norm in Canada (Walkinshaw, 2011).

Wells and colleagues (2008) conducted a literature review of Patient Navigator programs for cancer populations (including 45 articles) which demonstrated great variation. What was described as consistent characteristics were the following:

- Patient navigation is provided to individual patients for a defined episode of cancer-related care.
- Although tracking patients over time is emphasized, patient navigation has a definite endpoint when the services provided are complete.
- Patient navigation targets a defined set of health services that are required to complete an episode of cancer-related care.
- Patient navigation services focus on the identification of individual patient-level barriers to accessing cancer care.
- Patient navigation aims to reduce delays in accessing cancer care services, with an emphasis on timeliness of diagnosis and treatment and a reduction in the number of patients lost to follow-up.

With the aim of exploring the characteristics and outcomes of navigation programs for Indigenous people with cancer specifically, researchers in Australia conducted a review of the literature (Whop et al., 2012). Their search yielded eight articles, all based on two programs in the United States. Emphasis of the Native Sisters Program was on:

- Increasing recruitment to mammography screening and attended screening appointments.
- Assisting women in preparing questions to ask healthcare professionals.
- Supporting the patient’s family, if required.
• Assisting patients to navigate their way through the healthcare system if a cancer diagnosis was made.

The aim of the other program, Walking Forward Program, that was highlighted in Whop et al.’s review was towards reducing cancer mortality rates. This was achieved through delivering culturally appropriate community education relating to the importance of screening and early detection, as well as research. The Patient Navigators contributed to empowering community members about the clinical experience, and furthermore assisting with: transportation, scheduling multiple appointments on one day instead of over a longer period of time, facilitating child-care, looking into insurance issues or financial support, and facilitating communication both in terms of translation and explaining health terminology.

**Customizing the Patient Navigator role for FNIMul populations in Ontario**

“many Aboriginal people don’t trust, and therefore don’t use mainstream health care services”
(Health Council of Canada, 2012, para. 2)

CCO is the provincial government’s cancer advisor. CCO implements provincial cancer prevention and screening programs, and develops and implements quality improvements, standards and accountability for cancer care. Within CCO, the Indigenous Cancer Control Unit (ICCU) works directly with provincial FNIMul groups to implement CCO’s Aboriginal Cancer Strategy III (2015 – 2019), the vision of which is to improve the performance of the cancer system with, and for, FNIMul peoples in Ontario in a way that honours the Indigenous Path of Wellbeing. One key initiative which begun during CCO’s second Aboriginal Cancer Strategy (2012 – 2015), and which is still very much a part of the Aboriginal Cancer Strategy III, is the Indigenous Navigator Program.

In response to increasing cancer burden among FNIMul, CCO now funds a network of 10 Indigenous Navigators across Regional Cancer Programs (RCP) in Ontario. The functions of the RCPs are to respond to local cancer issues, coordinate care across local and regional healthcare providers, and work to continually improve access to care, wait times and quality. Figure 1 illustrates the location of the RCPs in relation to FNIMul communities and organizations in the province.
Figure 1. FNIM Communities, Organizations, and Regional Cancer Programs in Ontario

Results

Although the Indigenous Navigators are physically based at the RCPs (large tertiary hospitals), the clients and communities they serve are spread across the region. Within their regions, the Navigators work as a liaison and advocate for on- and off-reserve First Nations communities, Métis councils, Inuit community members and other FNIMuI organizations (e.g., Aboriginal Health Access Centres, Indigenous Friendship Centres). The populations they serve can often vary greatly in distance traveled to receive cancer care—some patients may live in remote communities, while others are based in major urban centres.

The Indigenous Navigators are responsible for facilitating and coordinating access to cancer services, including palliative and supportive care, for FNIMuI people with cancer and their families. Throughout a patient’s cancer journey, the Navigators liaise and advocate for their needs within the cancer centre, and with others working across multi and interdisciplinary health professional teams involved in cancer care. The logistical elements of receiving cancer care, including scheduling, transportation and paperwork, can be a significant barrier to achieving positive health outcomes of FNIMuI living with cancer (Lavoie et al., 2016). The Indigenous Navigators help patients navigate claims and reimbursements from the Non-Insured Health Benefits Program (for Status First Nations and some Inuit), share information about available transportation initiatives (e.g., Canadian Cancer Society’s Wheels of Hope) and arrange the necessary services and equipment for patients who wish to receive
treatment (including end-of-life care) at home. For patients who might have difficulty understanding health care providers in English or French, the Indigenous Navigators arrange for translation services (e.g., Ojibway, Oji-Cree, Inuktitut). Given an increasing recognition of the importance of health literacy, it is useful to consider the concept in relation to priority health issues for FNIMuI. Navigators play an important role as knowledge brokers within communities and the patients and families they work with. Health literacy studies show that a large part of the Canadian population has substantial difficulties with reading and numeracy associated with health-related information and tasks; similarly, health literacy independently predicts health outcomes even after controlling for socioeconomic position (Beauchamp et al., 2015). The foundation of the Indigenous Navigator role is to also address cultural and spiritual needs to make the cancer journey a culturally safe experience for FNIMuI patients and families. The key to understanding is the recognition of the great diversity among FNIMuI people and communities. This includes ensuring that the individual’s goal and wishes are respected throughout their cancer treatment. Within the RCPs, they work to ensure that safe spaces are available to patients. In some centres, this includes designated rooms for reflection or ceremonies (e.g., Windóçâge Community Room in Ottawa, Medicine Lodge at Health Sciences North). The Indigenous Navigators also coordinate access to spiritual support and traditional medicines by connecting patients with Elders or traditional knowledge keepers.

In addition to supporting cancer patients, the Indigenous Navigators also play an important role in the education of health care providers and other cancer program staff in their regions. They work to raise awareness of the unique needs of the communities they serve. In alignment with Truth and Reconciliation Commission Report Calls to Action (2015), Indigenous Navigators also emphasize the importance of cultural safety within the health system and point staff to resources (e.g., CCO’s Indigenous Relationship and Cultural Competency courses). By communicating regularly with regional partners, they ensure that the needs of FNIMuI patients are not overlooked during the planning of regional or provincial initiatives. In Fraser’s (2017, pages 6-7) article about one of the Indigenous Navigators, she describes how Kathy MacLeod-Beaver “builds face-to-face relationships with other service providers so she can provide personal introductions when her clients need their services.”

Within Ontario, certain regions have expanded Navigation beyond the cancer system. For example, Health Sciences North in Sudbury has created a formal process to refer patients to Patient Navigators at three Indigenous health centres in the North East region. In the Champlain region, Tungasuvvingat Inuit provides health and social services Navigators to Inuit, including families undergoing treatment at the Children’s Hospital of Eastern Ontario.

**Program Impact**

In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples. (TRC, 2015, page 7)

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By 2016/2017, each of the Indigenous Navigators systematically reported their annual performance in terms of activities and outcomes within set described initiatives as outlined in Table 1. This type of reporting has enabled a ‘at a glance’ assessment of areas of strength and challenges in the regions were the Navigators work. This method of data generation is practical but does not accurately capture the work of the Indigenous Navigators in their entirety.

**Table 1.**

*Initiatives and examples of activities and outcomes of the Aboriginal Navigators 2016/2017*

<table>
<thead>
<tr>
<th>Initiatives/Deliverable(s)</th>
<th>Examples of Activities</th>
<th>Examples of Indicators and Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom assessment and management</td>
<td>Promote use of standardized symptom assessment tools for FNIM cancer patients [(e.g. Edmonton Symptom Assessment System (ESAS)] Wholistic Assessment includes addressing the four domains of self (&amp; family): mental, emotional, spiritual and physical.</td>
<td>Collection of anecdotal data/feedback on patient experience Patients and families are supported by Traditional Healers, Cultural Advisors, Elders.</td>
</tr>
<tr>
<td>Supporting FNIMuI patients to access palliative care services (in and out of hospital and including both traditional and non-traditional)</td>
<td>Continue to identify appropriate resources to support FNIMuI patients, families and communities Partnering with local FNIMuI communities to build community capacity and development for customized approaches to facilitate culturally appropriate palliative care services. Facilitating access to Pallium Canada’s Learning Essential Approaches to Palliative Care</td>
<td>Indigenous Palliative Care Team developed to address barriers to accessing equitable palliative care (SWLHIN, 2018). Number of resources identified: - agencies/services utilized by patient and families - Elders/knowledge keepers referrals Building capacity for FNIMuI community service providers to manage their own palliative care needs and people.</td>
</tr>
<tr>
<td>Provide support and increase awareness of cancer care for FNIMuI patients with cancer and their families</td>
<td>Continue to contribute to the regional FNIMuI Patient Navigation package ensuring the most up-to-date resources are includedThe development of unique programs, resources and tools based on the knowledge of and sensitivity to the community</td>
<td>Educational resources developed (e.g. FNIMuI Smudge video to promote Sacred bundle) Establishing private breast screening events for FNIMuI communities with local hospitals.</td>
</tr>
<tr>
<td>Engagement with Aboriginal Navigator network, End of Life Care Networks and/or Regional Palliative Care Program</td>
<td>Support and participate in FNIMuI Advance Care Planning community education and training</td>
<td># Advance Care training sessions held</td>
</tr>
<tr>
<td>Working with Regional Aboriginal Cancer Lead to support and develop strategies for earlier primary care engagement with FNIM patients</td>
<td>Continue to assist in the development of a Regional strategy with FNIMuI partners to increase awareness and access to screening</td>
<td># Finalized RCP Aboriginal Cancer Strategy # First Nations communities to hold engagement sessions</td>
</tr>
</tbody>
</table>
This paper does not present the number of interactions with patients and their families over the 2016/2017 time period since several factors can influence this such as duration the Indigenous Navigator has been in place at the RCP, or the proportion of Indigenous cancer patients in the caption area compared to others. The variation across sites does not necessarily determine higher or lower impact. For example, considerable time is spent developing relationships within the health system and within communities. Those engagements are not always captured or measurable, however are necessary for being impactful with patients and their families. Figure 2 describes some of the observations and reflections the Indigenous Navigators noted in their annual reports. These comments also speak to areas of concerns and aspirations.

**Figure 2.** Indigenous Navigators' reflections of strengths, challenges and aspirations described in their annual reports
Conclusion

We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients. (TRC, 2015, page 7)

CCO’s Indigenous Navigators provide support and advocacy for FNIMuI patients and families by facilitating and coordinating access to cancer services for palliative and supportive care, addressing cultural and spiritual needs, and networking with FNIMuI and non-Indigenous partners to make the cancer journey a culturally safe experience for FNIMuI patients and their families. The Indigenous Navigators in Ontario go beyond the programs available for general populations described in Wells et al (2008) and are more comparable to the programs described for Indigenous populations in the United States highlighted by Whop et al (2012). The cancer burden among FNIMuI in the province suggests increased use of the cancer system therefore now is the time to highlight the work of the Indigenous Navigators, encourage the continuation of their successes, and respond to the challenges they observe.

Further recommendations for organizations to act on include:
- Hiring local artists to include artwork at main entrances into hospitals and cancer centres
- Include Indigenous specific services at kiosks at information booths
- Host regular in services with local FNIMuI community service providers to understand their programs and develop meaningful relationships.
- Leaders and hospital staff to visit local FNIMuI communities to ‘get to know’ your partners
- Initiate regular e-broadcasts across your organizations highlighting the strengths of Indigenous communities and their impact on the medical field (i.e. aspirin came from the red willow tree)
- It is imperative that health systems, leaders and providers engage directly with FNIMuI communities

We recognize that the Indigenous Navigators in many aspects are someone who specifically addressed barriers to care (Antone, 2018). Now compound those barriers with the complexities of Indigenous specific determinants of health: colonization, globalization, migration, cultural continuity, territory, access, poverty, and self-determination (Greenwood et al., 2018). We urge health care leaders, staff and other health system partners to join us in working towards a better tomorrow with and for the Original People of this land we call Canada. Building meaningful relationships with local communities based on mutual respect, together we can help remove the barriers that prevent Indigenous people from achieving health and wellness.
References


Logan A. 2017, December 30. Personal communication.


