Service Providers' Perceptions of Support Needs for Indigenous Cancer Patients in Saskatchewan: A Needs Assessment

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Abstract

Background: In Saskatchewan, Canada, Indigenous cancer care services at the municipal, provincial, and federal levels are intended to improve quality care but can result in a complex, fragmented, and multi-jurisdictional health care system. A multi-phase needs assessment project was initiated to document Indigenous cancer care needs. Guided by Indigenous patient partners, clinicians, academics, and policy makers, the present study reflects a needs assessment of Indigenous cancer supports from the perspectives of cancer care service providers.

Methods: Qualitative data were collected through three group interviews with 20 service providers for cancer patients and their families at three Saskatchewan cities. Participants included chemotherapy and radiation nurses, social workers, a patient navigator, dieticians, and practicum students. A semi-structured interview guide was used to conduct the sessions to allow for freedom of responses. Data were recorded, transcribed verbatim, and analyzed using thematic analysis.

Results: Service providers' perspectives were categorized into five themes: 1) addressing travel-related issues, 2) logistical challenges, 3) improvements to Indigenous-specific health care supports, 4) cultural sensitivity in health care, and 5) consistency in care. Supports differed for the two Indigenous groups, First Nations and Métis. Service providers made recommendations regarding how needs could be met. They saw language translation providers and Elder supports as important. Travel recommendations included medical taxis accommodating for more breaks to alleviate the uncomfortable side effects of cancer treatment and Indigenous-specific accommodations be provided. These recommendations aligned with supports that are available in four other Canadian provinces.

Conclusions: These results identified gaps in supports and outlined recommendations to address barriers to cancer care from the perspectives of service providers. These recommendations may inform evidence-based health system interventions for Indigenous cancer patients and ultimately aim to improve cancer care services, quality of life, and health outcomes of Indigenous patients throughout their cancer journey.

Background

First Nations, Inuit, and Métis are ethnic groups that comprise Indigenous peoples in Canada. Within these groups, the rates of cancer diagnoses are disproportionately rising [1, 2] and their survival rates are comparatively lower than Canada's non-Indigenous population [3]. In the province of Ontario, the rate of new cancer cases for First Nations people has nearly doubled from 1968 to 2001 [4]. In Saskatchewan, First Nations specifically from the northern regions, are overrepresented in cancer diagnoses and have higher rates of late-stage cancer diagnoses than First Nations and non-Indigenous people residing in the south [5]. With regards to mortality, First Nations have poorer survival compared to non-Indigenous Canadians for 14 of the 15 most common cancers [3]. Further, cancer cases are expected to rise as the Indigenous population ages [1–5]. These findings suggest that cancer is an increasingly relevant health

issue for Indigenous peoples in Canada making optimal care for Indigenous cancer patients a significant concern to address.

Cancer diagnosis, treatment, and aftercare may be especially challenging for Indigenous patients and their families due to unique issues faced by Indigenous peoples in Canada [6]. First Nations registered under the *Indian Act* and Inuit recognized by an Inuit land claim organization receive health coverage through the Non-Insured Health Benefits (NIHB) program that is provided by the federal government's Department of Indigenous Services Canada. Specific to cancer care, coverage includes medical supplies and equipment, medical transportation, and reimbursement for accommodations in circumstances when health services are not locally available. However, the federal government does not provide this coverage for Métis; instead, Métis registered through one of the five provincial Métis organizations can apply for coverage for relevant initiatives if their organization offers such supports. Aside from medical coverage, municipal health care centres and provincial health organizations may offer additional Indigenous-specific programs to provide services such as cultural and spiritual support. The presence of Indigenous health programs and services at the municipal, provincial, and federal levels are intended to ensure improved quality care but can result in a health care system that is complex, fragmented, and multi-jurisdictional [7]. Consequently, cancer diagnosis, treatment, and aftercare may be especially challenging for Indigenous patients and their families.

Geographical differences are an additional challenge for many Indigenous cancer patients. According to the 2016 Canadian census, 38.9% of Indigenous peoples live in rural areas, 20% in small population centres (1,000–29,999 people), 10.8% in medium centres (30,000–99,999 people), and 30.3% in large population centres (over 100,000 people) [8]. Therefore, the majority of Indigenous peoples must travel to receive care. While some provinces that have cancer screening programs that address geographical barriers, cancer treatment centres are predominantly in cities with large population centres. To address geographical barriers for First Nations and Inuit patients, the Non-Insured Health Benefits (NIHB) program and some Métis Nation organizations offer coverage and support for Indigenous patients required to travel [6, 9].

Despite general supports and some Indigenous-specific cancer services, there is evidence of unmet needs for cancer support services for the Indigenous population [10–12, 7]. Prior to our research, there had been no systematic assessment of the cancer care support services for Indigenous people in Saskatchewan, Canada. To address this gap, a multi-phase needs assessment project was initiated titled *Sâkipakâwin*, the Cree word for budding or sprouting. This research project was guided by an advisory team of Indigenous patient partners, clinicians, academics, and policy makers. Using a needs assessment methodology [13], the purpose of the present study was to identify the support needs of Indigenous cancer patients and their families from the perspectives of cancer service providers. Identifying and prioritizing these needs are the first steps to implementing evidence-based health system interventions in supporting Indigenous patients and their families during cancer diagnosis, treatment, and follow-up.

Methods

Setting

Saskatchewan is an exemplary province for identifying Indigenous cancer needs because it encompasses a large population of the two most populous Indigenous groups, First Nations and Métis, and the majority of these groups live in remote, rural, or small population centres [8]. In comparison to other provinces (vs. territories) in Canada, Saskatchewan has the second highest proportion of Indigenous peoples, with 16.3% of the population belonging to at least one Indigenous group. Of this population, 65.5% are First Nations (65.5% Registered Indian; 34.5% non-Registered Indian) and 33.1% are Métis (remaining proportion represent those with multiple Indigenous identities). Representation of these specific groups are significant, as each group receives different medical coverage; that is, Registered First Nations receive federal coverage through NIHB while Métis receive the same coverage as non-Indigenous people, or registered Métis citizens may apply for relevant benefits through their Métis organization. However, within Saskatchewan, all groups may choose to access Indigenous Elder support and translation services through the provincial health authority's First Nations and Métis Health Services [14]. Regarding geography, 62% of the Indigenous population reside outside cities where cancer treatments are generally offered [8], indicating that most Indigenous peoples in Saskatchewan must travel in order to receive cancer care.

Participants

For the current study, qualitative data were collected through group interviews with service providers for cancer patients and their families in Saskatchewan. Three group interviews were conducted with a total of 20 participants. Interviews took place at the Saskatoon Cancer Centre (6 participants), the Allan Blair Cancer Centre in Regina (8 participants), and the Community Oncology Program of Saskatchewan (COPS) in Prince Albert (6 participants). Inclusion criteria for service providers were health care professionals from cancer care facilities such as hospitals, cancer centres, and COPS centres. Providers included chemotherapy and radiation nurses, social workers, a cancer navigator, dieticians, and practicum students. Providers were recruited through a research coordinator employed by the Saskatchewan Cancer Agency and by a patient and family advisor on the research team. Each needs assessment phase required independent research ethics approval, to which the current study was approved by the Behavioral Research Ethics Board (REB) at the University of Saskatchewan (#18–105).

Procedure

Group interviews were facilitated by two researchers in the aforementioned cancer care settings. After participants provided written consent to participate, the group interview began by asking general questions about Indigenous peoples within the health care system (e.g., "How do you identify that a patient is Indigenous?"). A semi-structured interview guide (see Appendix) was used to conduct the remainder of the session to allow for freedom of responses. Each group interview was approximately one hour. Data were collected using an audio recorder and interviews were transcribed verbatim by the University of Saskatchewan's Social Science Research Lab. Aside from a meal that was provided during the interviews, no compensation was offered for participating in the study.

Transcriptions were reviewed by the researchers and analyzed using thematic analysis. The transcript from each group interview was independently coded by two researchers (authors JS and AA) and final themes were reviewed by the coders and author TC. Coding was conducted and validated using Braun and Clarke's (2006) approach [15]: initial codes were identified and collated into potential themes, themes were reviewed and potential coding conflicts were addressed, and analysis was finalized by generating descriptive names for themes and subthemes. Braun and Clarke's 15-point checklist of criteria for good thematic analysis was also used [15]. Criteria includes ensuring that researchers were active in the research process, that balance between analytical narratives and illustrative extracts are provided, and that data were interpreted rather than simply described.

Results

The needs of Indigenous cancer patients were identified by service providers' perceptions of barriers to care and limitations of existing formal supports specific to Indigenous peoples. Needs were identified and categorized into five themes: 1) addressing travel-related issues, 2) logistical challenges, 3) improvements to Indigenous-specific health care supports, 4) cultural sensitivity in health care, and 5) consistency in care. To note, quotes will reference participant (P) and group interview (GI) numbers.

Theme one: addressing travel-related issues

Participants highlighted several challenges for Indigenous patients living in rural and remote communities. Support needs regarding transportation and accommodations were identified in light of these challenges and summarized in the following sub-themes: properly resourced medical taxis, Indigenous-specific accommodations, and expansion of formal and informal supports to Northern communities.

Properly resourced medical taxis

Participants noted from previous discussions with First Nations cancer patients that there were concerns with the medical transportation service provided by the NIHB. Concerns ranged from issues relevant to all patients, such as passengers smoking inside the medical taxi, to issues specific to passengers with cancer, such as a lack of properly resourced vehicles or travel itineraries that did not meet the unique needs of cancer patients. For example, patients undergoing chemotherapy may require more rest stops in order to alleviate the side effects of their treatment, and patients with cancers that may be particularly uncomfortable during travel (e.g., anal cancer) should also be accommodated (e.g., more rest stops, appropriate seating). The following excerpt relays the experience of using medical taxis as recounted by one participant:

I've had people tell me that they're crammed into a vehicle of some kind, and if you've got some side effects like diarrhea and that kind of thing along the way there's no place to stop and go to the bathroom. They're not feeling well and they're on some crappy road that is [a] very long distance... (GI 1, P 4)

Although discomfort may be experienced by any cancer patients, the medical transportation service by the NIHB is exclusive to First Nations patients. As discussed by participants, the service ought to provide support beyond its utility of transport by inquiring about and accommodating the specific travel needs of First Nations cancer patients.

Indigenous-specific accommodations

Participants noted that accommodations for cancer patients known as “cancer lodges” were not frequently or often being utilized by Indigenous patients (“*That’s not where there the Indigenous people are staying*”; GI 1, P 2) despite being the only specific accommodations that cater to the needs of cancer patients undergoing treatment. Several participants relayed why First Nations and Métis patients are finding refuge elsewhere. One provider said:

...we have had some stay there and specifically state, they felt uncomfortable. I mean, we don’t have control over the other people who stay there, and maybe they’re racist. I’ve heard that from several patients, Indigenous ones, that that was an uncomfortable place for them to stay, which is too bad. (GI 1, P 5)

Rather than staying at the cancer lodges, participants from Prince Albert noted that First Nations patients were going to an Indigenous-specific boarding home that offers medically-approved lodging and transportation to registered First Nations patients. This service is not offered in other cities that house the cancer centres, and participants stated that patients were instead opting to stay at hotels. While both hotels and the boarding home for Indigenous patients may provide more comfort to patients, participants noted some limitations with these accommodations:

The problem with Spruce Lodge for our cancer patients is that it is a shared bathroom, so you’re exposing everybody in Spruce Lodge to chemo, and you’re also exposing those patients to everybody else’s bacteria and stuff like that... Now it has shifted that a lot of the chemo patients will stay in hotels as opposed to staying at Spruce Lodge, which has worked out a lot better. However, depending on which hotel they stay at is dependent on how much sleep they get the night before kind of thing. Cause lots of our people will come in the day before, and we’ve had people say, “I just didn’t sleep last night, we stayed at whatever hotel and it was loud in the hotel”. (GI 2, P 4)

Providers agreed that addressing the above issues would be improved by Indigenous-specific lodging that accommodated those undergoing cancer treatments. An exemplar of this conclusion is summarized by one participant, “*If we can’t provide [cancer care] in the community, then the least we can do is accommodate here some place*”. (GI 1, P 2)

Expansion of formal and informal supports to Northern communities

Many barriers identified by service providers concerned patients having to travel long distances and for sometimes extensive time periods. Being away from the community holds psychosocial implications for

Indigenous patients that can compromise their willingness to receive cancer treatments. This circumstance is illustrated with the following quote:

...I did work for a northern health organization... where we would have people who would just choose not to get treatment because of the time that it would take them away from their community. Just the difficulties with family and the community, you know, being away from home. (GI 3, P 5)

Due to numerous travel barriers, providers from all group interviews determined that formal supports, such as some cancer treatments, and informal supports, such as home care and nutrition services, requires northern expansion (e.g., “*So all of our treatment facilities are basically south of halfway of our province. So yeah, additional COPS centres [community oncology programs] or health facilities, in more locations*” [GI 1, P 2]). While expanding COPS centres would be ideal to delivering basic outpatient care and treatments (e.g., chemotherapy, radiation), one patient notes that training health care providers in northern communities to deliver similar services could be another option. As one participant explains:

One thing that we do find is they need more support in their home communities. Such as line care, for example... Some of the communities aren't comfortable, I guess, with removing those lines and flushing those lines appropriately. As a result, those patients have to remain with us for a couple days so that homecare here in the city can remove the line... So education to the communities of how to care for these lines would be valuable I think. (GI 3, P 3)

An additional solution to decreasing travel was suggested by one provider who stated that oncology appointments could be provided by distance if the province's TeleHealth was effectively utilized: “*I think a lot of the centres too, in the north, that Telehealth is down. It's not working consistently, it's not a reliable tool to be used*”. (GI 2, P 4) Together, participants determined that further training for northern health care providers on out-patient cancer care, expansion of cancer treatment programs in the north, and reliable medical appointment technology would reduce the need for patients to travel from their communities for cancer care.

Theme two: logistical challenges

A significant focus of each group interview was about the complexities of Indigenous patients accessing existing supports, and that these complexities often compromised the benefits that the supports were intended to deliver. Three sub-themes emerged regarding needs that addressed logistical issues: coordinating care with NIHB (travel, prescriptions) for First Nations patients and reimbursing First Nations patients for medications and/or travel up-front.

Coordinating care with NIHB (travel, prescriptions) for First Nations patients

To reiterate, the NIHB is medical coverage by the federal government that applies only to Registered First Nations and Inuit (i.e., excludes Métis). Although NIHB is intended to provide support (e.g., travel coverage), participants consistently noted frustrations when having to contact employees of the program.

Any additional effort to advocate for patient supports were often denied by the NIHB Program, and the program's rigid regulations surrounding medical travel.

One provider stated that their issues with contacting the NIHB Program was often the time required to communicate with those who run the program when coordinating coverage on behalf of the patient:

...my longest [time on hold on the phone] was an hour and 21 minutes waiting to get through to them. So that's formal resources being used inappropriately. When you finally get through to them, sometimes they can't help – because you're phoning a call center, these aren't people that dedicated their lives to Indigenous issues. (GI 1, P 1)

A second provider notes that an additional weakness of this communication model is that there is no consistent contact with NIHB employees. They state that this leads to time loss because providers are "repeatedly calling [the NIHB Program] back" regarding the same patient and that they would often be "getting a different person" and therefore "taking a lot of time to re-explain the situation and re-advocating for the same things". (GI 1, P 2)

Specific to travel, providers discussed several logistical issues. One participant stated having to advocate for a patient in order to receive travel deemed unnecessary by the NIHB Program. As one provider explains:

Well on one phone call I may have to advocate for taxis in town, whereas the next one I'm getting told "no, because they're close enough to the hospital that you shouldn't need a taxi." So then I'm fighting about that... So if we don't know the system, then our patients aren't getting the services needed. (GI 1, P 1)

An additional travel-related issue regards the relatively limited timeframe in which travel coverage can be coordinated, as medical travel provided through the NIHB must be arranged at least two weeks prior to the appointment. Participants stated that the timeframe required to schedule medical travel was particularly burdensome if care was urgent or if a last-minute appointment time became available to First Nations patients. The limited timeframe to submit requests for NIHB-covered patients also extended to receiving medications, indicating that this logistical issue is impeding participants from taking their medications ("then there's that whole wait time and people not getting their supportive meds in a timely fashion that they need it... It's very, very challenging"). (GI 1, P6)

Reimbursing First Nations patients for medications and/or travel up-front

Participants noted an economic barrier experienced by some registered First Nations patients was the delayed medical coverage for their cancer-related expenses. A discussion between participants illustrates this issue (GI 2):

P1: *...there was lots of First Nations who travelled from reserves that were 800 kilometers from Saskatoon so then they need to fly in, they need to have a hotel stay and stay overnight – it's a major expense for an*

individual. It seemed to be a somewhat complicated funding structure because they'd go through the band office and that would have to be approved. It never seemed easy for those people to get to the clinic

P2: Sometimes it's a fight to have that money come up front and then have to submit all that paper or receipts or whatever and then get that payback. But that's subjective to each nation, right?

P3: And if they don't have the actual money to put up front-

P1: Yeah, some don't even have it.

P3: They can't go, 'cause getting money after they come back isn't doing them any good, 'cause they haven't any to get here.

As stated in the dialogue, travel or medical coverage through NIHB may still not be accessible to First Nations patients from low-income households because of the up-front costs. Participants highlighted that the current model of medical coverage is not adequate to accommodate the patients who require this support the most. Instead, expenses should be covered directly through funding body (e.g., the NIHB Program).

Theme three: improvements to Indigenous-specific health care supports

Participants identified limitations within existing services available to Indigenous patients within hospitals and other health care facilities in the province. The following sub-themes outline proposed improvements to: Indigenous language interpreters, elder support, and standardizing identification of Indigenous identity to ensure that Indigenous-specific health Care supports can be offered.

Indigenous language interpreters

Adequate interpretation was repeatedly discussed, with one participant asserting that *"language is one of our biggest barriers, and trying to rectify that would be a huge step in the right direction"*. (GI 1, P1) Providers acknowledged that interpretation was offered for some First Nations languages but noted limitations with translation services. Despite having access, there were not enough translators to meet the demand of patients. Increasing the number of interpreters was suggested by one participant: *"even though we do have interpreters, I think having additional, having enough or having more would be very beneficial"*. (GI 3, P6) Another provider discusses including more Indigenous languages for language translation. They state: *"Yeah, we do have regular struggles with Dene because it's – We don't have as many. Like we have a few, even staff that can speak Cree in the building at any given time. But Dene seems to be the more common struggle"*. (GI 3, P 5)

An additional concern was that translators were not immediately offered to Indigenous patients with medical companions. One participant expressed that translators were still necessary because they were unsure of the quality of information that family members translated to the patient: *"...a lot of times we get translators from the community coming in, and you never know how much information is actually getting*

through to the patient, which is bothersome to me.” (GI 1, P5) Participants asserted the importance of interpreters particularly for their training in medical translation, which is a skill that medical companions do not necessarily have. The following participant states their recommendation:

I almost wonder too, yeah, if just – especially maybe their first appointment with an oncologist in Saskatoon, if there’s a translator that’s not family present at that, and it’s just not questioned. This is just how we do things, this is how it is, they’re a medically trained translator, they’re here no matter what, kind of thing. (GI 3, P 4)

A final proposed solution to address issues with current language translation supports models a current service offered to patients who speak non-Indigenous languages. The provincial health agency uses MCIS Language Services, an external organization that provides professional interpretation services 24 hours a day, seven days a week for patients. This organization does not offer translation in any Indigenous languages, but a comparable system was proposed. The following details this service by one participant:

It has to be pre-arranged. There’s a 1-800 number. I mean you could contact them and you may get same day service, it’s just not immediately... Because even with Cree and Dene, a lot of things are difficult, it’s not just the language it’s the medical aspect... then not only are they [the telephone interpreter] fluent in the language, but also fluent in medical language too. (GI 3, P 5)

Elder support

Elder support that is offered to Indigenous patients through the province’s First Nations and Métis Health Services was praised by service providers for providing patients with advocacy, representation in health care, and culturally relevant supports. One participant notes:

He’s amazing and he’s got lots of knowledge, he helps guide - he’s one of those people who’s a key - there’s the traditional pathways for Indigenous pathways and then we have the mainstream way of doing things, he serves as a “Let’s find a way for both”. (GI 2, P 5)

However, Elder support is exclusively offered in hospitals because the cancer centres are a separate institution, and those using medical travel through the NIHB Program are only provided transportation to and from the location where the patient received cancer care. Consequently, First Nations patients using medical travel may not have access to Elder support.

Providers also discussed needs for stronger relations between the provincial health agency and influential members within Indigenous communities, such as Elders. The advantage is that Elders can assist with advocating for health and wellness through education such as cancer prevention. To facilitate this, health officials need to *“try to bridge the gap of getting some buy-in from the community level” in order to have community members advocate to “to try and help get people out and motivate them to take action for their health...”* (GI 2, P 4)

Standardizing identification of Indigenous identity to ensure that Indigenous-specific health care supports can be offered

Indigenous specific supports from First Nations and Métis Health Services may be suggested by service providers, but participants stated that no systematic approach existed for identifying Indigenous patients that might benefit from this service. The lack of formal approach was evident from the varied answers that providers gave when asked how they determine if a patient is Indigenous. Answers included patient's self-identification; asking the patient; judgements of the patient's racial identity, last name, or home address; and from observing registration numbers of Indian status cards from First Nations patients' electronic charts. This lack of reliable approach is problematic because individuals can be Indigenous without physical characteristics and last names provide no guarantee of Indigeneity. Further, a significant proportion live in large population centres (27.5% in Saskatchewan) [8], and other Indigenous groups such as Métis do not have Indian Status and thus do not have registration numbers. Participants concluded that the presence of Indigenous-specific services was a positive support, but that an emphasis on a methodical approach to identifying Indigenous patients was needed.

Theme four: cultural sensitivity in health care

Participants acknowledged that most health care providers are non-Indigenous, and that non-Indigenous providers are less likely to be informed on how to provide culturally relevant care to Indigenous cancer patients. Participants discussed how culturally relevant care could be better facilitated by the following themes

cross-cultural understanding for non-Indigenous service providers and Indigenous service providers in all stages of cancer care continuum.

Cross-cultural understanding for non-Indigenous service providers

Health care professionals in Saskatchewan are often obligated to complete Indigenous sensitivity training during post-secondary education or workplace in-services to facilitate cross-cultural understanding. However, as participant 5 (GI 2) states, "*It needs to be more than just an Indigenous sensitivity training that usually is typical of checked box... They facilitate a conversation about it but don't continue... doing more initiatives*". One initiative discussed was education on traditional healing methods to inform providers what it is, how it may be integrated with Western medicine, and how to discuss its integration with patients ("*...having a better understanding and respect for the holistic side of things too, to integrate them better, present all the options, make informed decisions*"; GI 2, P 4). Further, it could address potential stigma that providers have about non-Western treatment options ("*if you know a disease is curable but they're going to go traditional medicine, as medical professionals I think we have difficulty with that*"; GI 2, P3).

Indigenous service providers in all stages of cancer care continuum

To promote cultural sensitivity in health care, participants highlighted the need for Indigenous representation from cancer care providers. One participant emphasized the need for representation from both dominant Indigenous groups in Saskatchewan: *"[First Nations and Métis] have very different realities in terms of practically everything. Very different experiences, very different supports that they have access to"* (GI 2, P 7). The quote illustrates that the experiences of navigating the health care system will differ between First Nations and Métis due to the supports available to each group, but also, that their experiences differ because they are distinct cultural groups. This highlights the importance of avoiding a pan-Indigenous approach by ensuring that needs (e.g., representation) are met for the predominant Indigenous groups in the province.

Theme five: consistency in care

Participants issued concerns relating to inconsistencies in both formal and informal care providers. The consequences of inconsistencies are among the following two themes: consistency from service providers (i.e., formal supports) and consistency from travel companions (i.e., informal supports).

Consistency from service providers (i.e., formal supports)

Participants acknowledged that there are higher inconsistencies in care for Indigenous patients living in the rural and remote areas of the province because of unreliable virtual appointments through Telehealth. Oncologist care was noted to be particularly unpredictable for Telehealth appointments:

They're doctors, they're oncologists, but they're not their primary oncologist. And so they might go to telehealth in January and see their primary oncologist who've they've always seen, and then they go in February, March, April, May, and they see somebody different. And it may be a different person each time, let alone just one person. (GI 3, P 4)

Participants highlighted two virtues of consistent cancer care providers. One provider captured both strengths of consistency in the following quote:

... I think that transition [of primary care providers] for a lot of people, especially people from the north when you talk about trust issues, that is not good to have fill-in doctors come in. They don't have the same rapport. The stuff they talked about at one telehealth may not ever come up again. (GI 3, P 4)

When patients must consistently retell their experiences, they may fail to share all details and consequently, as discussed among participants, the provider would be unaware of key details that could assist the patient.

Consistency from travel companions (i.e., informal supports)

Travel companions are a valuable informal support to Indigenous patients and can also be helpful for conducting language translation. Despite their benefits, participants mentioned that communication issues can arise when patients bring a different medical companion for each appointment. For instance,

one participant posits that patients may selectively disclose information based on which companion accompanied them:

... I think the other problem that we've had too, is sometimes it is a daughter or son that comes down with their parent, or even a husband and wife, and the patient may not be comfortable talking about certain things in front of who've they've brought... Dad may be comfortable in front of one child and not in front of the other child (GI 3, P 4)

Another provider speculates that the inconsistency of health companions may be due to the limits of the NIHB Program. They state: *"...one of the biggest things that we always say to people coming to the Cancer Clinic is, "you can bring several family members with you. Whoever's gonna make you feel comfortable." Often many of the First Nations people are limited to one person to be able to come. To me that's not quite right..."*. (GI 1, P 4) To elaborate, because First Nations patients are only funded for one medical companion, the patient may be less likely to articulate their experiences to the provider in front of the sole companion. If multiple travel companions were funded to accompany the patient, family members would be less likely to rotate as travel companions and thus, facilitate better companion consistency.

Discussion

The experience of accessing and receiving cancer care for Indigenous peoples in Canada is often distinct from the experience of non-Indigenous Canadians because of geographic barriers, navigating different and often complex systems of medical coverage, and cultural differences with the Western medical system. To accommodate for these potential differences, some provinces in Canada offer Indigenous-specific cancer support [16], though in Saskatchewan, there were limited supports for Indigenous patients in general and no supports specific to cancer. In light of these limited supports, we conducted a needs assessment of Indigenous cancer supports through group interviews with cancer service providers. In our study, participants were aware of many unmet needs that Indigenous cancer patients experience and outlined recommendations for addressing these needs through five themes of support needs: 1) Addressing travel-related issues, 2) Logistical challenges, 3) Improvements to Indigenous-specific health care supports, 4) Cultural sensitivity in health care, and 5) Consistency in care.

While previous studies conducted in Canada have examined First Nations' barriers to cervical cancer screening in Ontario [17] and palliative care [18], service providers in the current study discussed their perceptions of barriers and the support needs to address the barriers for both First Nations and Métis cancer patients. Further, this study revealed perceptions of needs related to all phases of the cancer care continuum. Parallel themes between these studies include geographic and transportation barriers [17] and culturally-appropriate care [18]. Aside from these common barriers, the current study highlights additional barriers (e.g., lack of Indigenous representation within health care system) and ultimately, details the solutions to address these barriers. The current study also builds on previous research by including the cancer support needs of Métis. Considering the needs of Métis is significant because their

medical coverage is akin to non-Indigenous people (i.e., provincial government coverage only) whereas First Nations' coverage is through the federal government.

Recommendations for policy and practice

Recommendations included improvements to existing supports for registered First Nations patients (e.g., coordinating and utilizing medical travel) and First Nations and Métis health programs. Specifically, communication with the federal government's NIHB Program often led to lost time because of extensive wait times for service providers advocating for patients' unmet needs. An additional recommendation for the NIHB Program was to conduct direct billing when possible for covered expenses, as paying for reimbursable cancer care needs upfront are a barrier for First Nations people with low-income. This is particularly relevant considering that poverty rates are disproportionately higher amongst Indigenous peoples in comparison to the non-Indigenous population in Saskatchewan [19]. Another recommendation was having additional resources for Indigenous supports in hospitals and cancer centres such as language translation and Elder supports. In summary, Indigenous health care supports are recommended to be inclusive of Indigenous groups and accessible to Indigenous patients that receive care outside of the facilities where these supports are located.

Considering that two-thirds of the Indigenous population in the province of study reside away from the cities in which cancer care is primarily received [8], it is unsurprising that many of the barriers discussed by participants related to geographical issues. Recommendations for travel improvements included offering medical taxis that accommodated the unique needs of cancer patients, such as extending the duration of travel to allow for more breaks to alleviate the uncomfortable side effects of cancer treatment. Accommodations for Indigenous patients were also discussed, with participants emphasizing that Indigenous patients conveyed discomfort when staying at lodgings that catered specifically to cancer patients and were instead staying in places like hotels that did not provide these specialized supports. Participants recommended that Indigenous-specific accommodations be provided. This is not an unrealistic recommendation, as these supports are available in four other provinces in Canada [16].

Participants also recommended more Indigenous representation among service providers for offering culturally relevant support and for facilitating trust between patients and providers. Improving trust between Indigenous patients and health care providers is significant, as previous research demonstrates that Indigenous peoples tend to have mistrust towards the Western medical system [11] due to historical [20, 21] and ongoing racism experienced within the system [22]. Research with service providers in the province of Ontario demonstrates that systemic discrimination towards Indigenous patients is a barrier to health care, and also recommends the need for cultural safety training [23]. Importantly, representation should be increased for both First Nations and Métis because they are distinct cultural groups. To note, this recommendation requires initiatives from multiple health authorities or organizations because cancer care supports are often provided through different organizations (e.g., health authorities, cancer agencies).

An important context for our findings is that some issues for Indigenous patients that service providers noted would also be experienced by non-Indigenous patients; for instance, discomfort from staying in hotels (vs. cancer lodges) that are unequipped for patients with side effects of chemotherapy. The key difference is that the decisions of Indigenous patients accessing supports (e.g., accommodations) may be motivated by avoiding racism from non-Indigenous providers of formal supports. That is, using the accommodations example, the discomforts of staying in a hotel may be the same for both Indigenous and non-Indigenous cancer patients, but that Indigenous patients might choose the discomforts of a hotel over the discomforts of racism by staff or residents of the cancer lodges. Therefore, the lack of cultural safety within the health care system could amplify challenges beyond coordinating medical travel or discussing culturally relevant treatment options with service providers. This reiterates the need for interventions that address cultural safety such as Indigenous representation within the health care system and Indigenous sensitivity training for service providers.

Limitations

A limitation of our study is that the support needs were identified by non-Indigenous service providers and therefore, these needs may not be consistent with the needs proposed by those with lived experience (i.e., Indigenous cancer patients and their families). However, the barriers to care proposed in the current study address are reiterated from previous qualitative research examining the experiences of Indigenous cancer patients in Saskatchewan; for instance, issues with coordinating and up-front costs for medical travel [10], the lack of culturally-appropriate accommodations [24], and the absence of information and access to Traditional medicine [25]. The shared perceptions of barriers to cancer care from both Indigenous peoples and service providers highlight that these concerns are relevant to the population utilizing the health care system and those providing care within it. A strength of our study is that it discusses barriers specific to cancer service provider perceptions, such as logistical challenges for providers coordinating coverage with the NIHB program.

Another limitation was that participants were asked to discuss their perceptions and experiences of providing cancer care for Indigenous peoples rather than specifically with regards to each dominant Indigenous group in the province; that is, First Nations and Métis. Therefore, participants' discussion was predominantly focused on the barriers for First Nations patients and consequently, the recommendations to improving cancer care exclude the unique barriers that Métis experience in the health care system. Rather than asking questions from a pan-Indigenous perspective, future research should emphasize asking questions that distinguish between Indigenous groups because of the practical differences in experiences and access to cancer care. Due to our time constraints arising from conducting interviews with service providers during their workday, we were limited by our capacity to probe for how issues (e.g., travel, Elder support) may differ for First Nations and Métis cancer patients.

Conclusions

An advisory team of Indigenous patient partners, clinicians, academics, and policy makers identified that a research priority was to conduct a needs assessment of Indigenous cancer care in Saskatchewan from the perspective of cancer service providers. The results of the needs assessment identified gaps in supports and outlined recommendations to address barriers to cancer care for Indigenous patients and their families affected by cancer. These recommendations may inform evidence-based health system interventions for Indigenous cancer patients and ultimately aim to improve cancer care services, quality of life, and health outcomes of Indigenous patients throughout their cancer journey.

Declarations

The authors collectively declare that the research was conducted in the absence of financial or commercial interests.

Ethics approval and consent to participate

The current study was approved by the Behavioral Research Ethics Board (REB) at the University of Saskatchewan (#18-105).

Consent for publication

NA

Availability of data and materials

Data supporting the findings are outlined in the manuscript. For the privacy of the participants, transcripts of the data are not publicly available.

Competing interests

The authors collectively declare that the research was conducted in the absence of financial or commercial interests.

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Authors' contributions

GG and TC conceptualized and designed study; TC and AB conducted group interviews; JRS and AA analyzed the data; JRS wrote the manuscript; and all authors edited and approved the final manuscript.

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References

1. Elias B, Kliwer EK, Hall M, Demers AA, Turner D, Martens P, et al. The burden of cancer risk in Canada's Indigenous population: a comparative study of known risks in a Canadian region. *International journal of General Medicine*. 2011;4:699–709. doi:10.2147/ijgm.s24292.
2. Métis Nation of Ontario and Cancer Care Ontario. Cancer in the Métis people of Ontario: risk factors and screening behaviours. 2015. <http://www.metisnation.org/media/653628/mno-cco-report-screen.pdf>. Accessed 07 Dec 2020.
3. Withrow DR, Pole JD, Nishri ED, Tjepkema M, Marrett LD. Cancer survival disparities between first nation and non-aboriginal adults in Canada: follow-up of the 1991 census mortality cohort. *Cancer Epidemiology Prevention Biomarkers*. 2017;26(1):145–51.
4. Marret L, Jones CR, Wishart K. First Nations cancer research and surveillance priorities for Canada. Workshop Report. 2004 Sep 23–24. Cancer Care Ontario.
5. Alvi RA. Breast, cervical, and colorectal cancer survival rates for northern Saskatchewan residents and First Nations (Doctoral Dissertation). University of Saskatchewan. 1999.
6. Canada. Non-insured health benefits for First Nations and Inuit. 2020. <https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517>. Accessed 08 Dec 2020.
7. Horrill TC, Linton J, Lavoie JG, Martin D, Wiens A, Schultz AS. Access to cancer care among Indigenous Peoples in Canada: a scoping review. *Social Science Medicine*. 2019;238:112495.
8. Statistics Canada. Data from Statics Canada: *focus on geography series, 2016 census*. Statistics Canada Catalogue no. 98-404-X2016001. Ontario: Ottawa; 2017.
9. Métis Nation of Alberta. Medical accommodations. 2020. <http://albertametis.com/medical-accommodations/>. Accessed 30 June 2020.
10. Carr T, Sedgewick JR, Roberts R, Arcand L, Ali A, Groot G. A Patient-oriented study of Indigenous Peoples' experiences of cancer in Saskatchewan: a qualitative Narrative analysis using sharing circles. *CMAJ Open*. Forthcoming.
11. Groot G, Waldron T, Barreno L, Cochran D, Carr T. Trust and world view in shared decision making with Indigenous patients: a realist synthesis. *J Eval Clin Pract*. 2020;26(2):503–14.
12. Letendre A, Garvey G, King A, King M, Crowshoe R, Bill L, et al. Creating a Canadian indigenous research network against cancer to address indigenous cancer disparities. *JCO Global Oncology*. 2020;6:92–8.
13. Stevens A, Raftery J, Mant J, Simpson S. Health care needs assessment: the epidemiologically based needs assessment reviews. Vol. 1. Radcliffe Publishing; 2004.

14. Saskatchewan Health Authority. First Nations and Métis health service - about us. 2015. https://www.saskatoonhealthregion.ca/locations_services/Services/fnmh/service. Accessed 15 Sep 2020.
15. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
16. Groot G. An environmental scan of provincial cancer supports for Indigenous patients and their families in Saskatchewan. 2020.
17. Maar M, Burchell A, Little J, Ogilvie G, Severini A, Yang JM. & Zehbe I. A qualitative study of provider perspectives of structural barriers to cervical cancer screening among first nations women. *Women's Health Issues*. 2013;23(5):e319–25.
18. Johnston G, Vukic A, Parker S. Cultural understanding in the provision of supportive and palliative care: perspectives in relation to an Indigenous population. *British Medical Journal Supportive Palliative Care*. 2013;3(1):61–8.
19. Hunter G, Sanchez M. Child and family poverty in Saskatchewan: 2019 Research Report. Social Policy Research Centre. 2019. <https://www.uregina.ca/socialwork/sprc/assets/2019-Saskatchewan-Child-Poverty-Report.pdf>.
20. McCallum MJL. Starvation, experimentation, segregation, and trauma: words for reading Indigenous health history. *Canadian Historical Review*. 2017;98(1):96–113.
21. Moffatt J, Mayan M, Long R. Sanitoriums and the Canadian colonial legacy: the untold experiences of tuberculosis treatment. *Qual Health Res*. 2013;23(12):1591–9.
22. Tang SY, Browne AJ. 'Race' matters: racialization and egalitarian discourses involving Aboriginal people in the Canadian health care context. *Ethnicity Health*. 2008;13(2):109–27.
23. McConkey S. Indigenous access barriers to health care services in London, Ontario. *University of Western Ontario Medical Journal*. 2017;86(2):6–9.
24. Roberts RA. Stories about cancer among the Woodland Cree of Northern Saskatchewan (Doctoral dissertation). University of Saskatchewan. 2005.
25. Roberts RA, Groot G, Carr T. Decisions on cancer care by Indigenous peoples in Alberta and Saskatchewan: a narrative analysis. *Rural Remote Health*. 2020;20(4):1–9.

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