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# Understanding culturally safe cancer survivorship care with inuit in an urban community

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#### ABSTRACT

Cancer is a leading cause of death among Inuit. A legacy of colonialism, residential schools, and systemic racism has eroded trust among Inuit and many do not receive culturally safe care. This study aimed to explore the meaning of culturally safe cancer survivorship care for Inuit, and barriers and facilitators to receiving it in an urban setting in Ontario Canada. As Inuit and Western researchers, we conducted a descriptive qualitative study. We held two focus groups (n = 27) with cancer survivors and family members, and semi-structured interviews (n = 7) with health providers. Data were analysed using thematic content analysis.

Three broad themes emerged as central to culturally safe care: access to traditional ways of life, communication, and family involvement. Family support, patient navigators, and designated spaces were facilitators; lack of support for traditional ways, like country food, was a barrier. Participants were clear what constituted culturally safe care, but major barriers exist. Lack of direction at institutional and governmental levels contributes to the complexity of issues that prevent lnuit from engaging in and receiving culturally safe cancer care. To understand how to transform healthcare to be culturally safe, studies underpinned by lnuit epistemology, values, and principles are required.

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## Background

In Canada, there are three distinct Indigenous groups of people, First Nations, Métis and Inuit. Close to 47,000 Inuit, or three quarters of the Inuit population, live in their vast geographic homeland known as Inuit Nunangat in northern Canada [1]. Inuit Nunangat, the Inuktut term for "homeland", covers more than a third of Canada's land mass and half of its coastline. Dispersion of the small population across the vast landmass, with most communities only accessible by air year round, creates unique challenges for the delivery of healthcare, rendering Inuit some of the most medically underserved populations in Canada [2,3].

Cancer is the leading cause of death among Inuit, with lung cancer rates being among the highest in the world [4]. The geographic remoteness of Inuit communities means that much of cancer screening, treatments, and survivorship supports require Inuit to travel to urban health centres, separating them from their families, social networks, and communities [5]. For Inuit, healthcare is steeped in the Canadian legacy of colonisation, residential schools, and government policies that do not reflect Inuit cultural values and approaches to health and healing. Western approaches are alienating for most lnuit, who experience ongoing racism, stereotyping, and healthcare providers' lack of understanding of their cultural norms and values [6]. Consequently, for many lnuit, their trust and participation in cancer care may be eroded and hindered [7]. Fatalistic attitudes, fears, and community stigmatisation were found to prevent many Indigenous people from seeking cancer survivorship care in a systematic review [8] and while all 17 studies were conducted in the USA, similar experiences have been reported among Inuit [5].

Cancer survivors are people living with, through, and beyond a diagnosis of cancer [9]. They have specific care needs in each step of their cancer journey that may include diagnosis, treatment, symptom and comorbidities management, psychosocial support, rehabilitation, and end of life care [10,11]. Inuit cancer survivors in particular face distinctive challenges that have not been adequately addressed, including a lack of culturally safe services and the need to travel large geographic distances to receive healthcare in urban centres [2,3]. The literature describes further obstacles for Indigenous people travelling to urban centres for cancer care, including inadequate transportation and resources upon arrival, displacements of family

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members during treatments, and unsuitable accommodations after hospital discharge [12,13].

Culturally safe care is linked to an enhanced management of comorbidities and treatment side effects, higher screening rates, and better engagement in psychosocial supports to improve the overall quality of life and decrease healthcare costs [5,14]. Some interventions that aim to enhance culturally safe care have shown promise, such as patient navigation [15-18], educational and psychosocial interventions [19], and better communication [20]. However, most research studies examining culturally safe care for Inuit have been conducted from Western epistemological perspectives [21] which precludes the involvement of Inuit and Indigenous methodologies that consider the intersections of Inuit culture, history, ways of knowing, and epistemologies that honour oral traditions such as gualitative methodologies [22-24]. The aim of this study was to explore the meaning of culturally safe cancer survivorship care for Inuit in an urban setting in Ontario and barriers and facilitators for Inuit to receive that care.

#### Methods

In order to firmly ground the data in the subjective experiences and perspectives of participants, we conducted a descriptive gualitative research study with data collected through focus groups and individual interviews [25]. A descriptive gualitative approach is ideally suited for exploring phenomena where not much is known [26]; this approach is pragmatic rather than interpretive and seeks to represent the perspectives of participants while staying close to the original research question [25]. Accordingly, our approach was grounded in Chapter Nine of the Canadian Tri-Council Policy Statement on research involving First Nations, Inuit, and Métis Peoples [27] and Inuit-specific principles as outlined by Inuit Tapiriit Kanatami in the National Inuit Strategy on Research [28]. Our research approach was also governed by the Inuit values and principles that, for Inuit in Nunavut, are often expressed in Inuit Qaujimajatugangit (IQ) [29]. IQ is central to traditional knowledge, cultural identity, and collective purpose, linking Inuit philosophy to actions (29, p 2). Throughout our research process, we fostered an atmosphere of trust, cultural safety, and ethical spaces in which Inuit values were uplifted and prioritised. Recognising and respecting the importance of traditional cultural values, community engagement and trusting relationships, we took guidance from these policies and from our research partners (who include the authors of the paper) throughout the research process (see *Setting & Collaboration* for detail).

#### Setting & collaboration

Participants were from an urban Inuit population in Ontario and included Inuit living permanently in the city, as well as those who were temporarily relocated from Inuit Nunangat to receive cancer care. Two organisations partnered with us on this study: Pauktuutit Inuit Women of Canada and Tungasuvvingat Inuit. Pauktuutit Inuit Women of Canada is a national nonprofit organisation that represents and advocates for all Inuit women in Canada and works to improve the health status of individuals, families, and community. Tungasuvvingat Inuit is a provincial non-profit organisation that acts as a resource centre for Inuit in Ontario. It provides cultural and social support programmes aimed at promoting the health and wellbeing of Inuit.

Our collaboration was guided by principles of integrated knowledge translation (KT) and Indigenous knowledge translation [30]. Integrated knowledge translation is an approach where researchers and the anticipated users of the research, such as patients, practitioners, or policy makers, work together to codesign and conduct research that is mutually meaningful [31]. Indigenous KT recognises and honours the history Inuit have in developing and sharing their knowledge, such as oral traditions, community engagement, and reciprocal sharing, to understand and inform actions for community health and wellbeing [32].

#### Data collection

Focus group participants included Inuit cancer survivors and family members of Inuit with cancer. They were recruited by our partner organisations using posters and announcements during prior community events. To facilitate participants' attendance, we scheduled two focus group meetings on a weekend at an event room in an Inuit community building where we provided bus vouchers and on-site childcare. Consent forms and printed information about the study were provided in English and Inuktut. An Inuk interpreter co-facilitated the group meetings in Inuktitut with a Western researcher (WG) and an Inuk counsellor was present throughout the sessions for support. During the discussions, participants had the opportunity to engage in a traditional craft activity, either sewing seal-fur earrings or constructing seal-fur key rings. Craft materials were supplied and an Inuk artist provided instruction and assistance to participants, as needed. We used a semi-structured interview guide with guestions that explored the meaning of culturally safe cancer care

and participants' experiences with receiving cancer care in an urban setting.

The focus group meetings were each two hours long, separated by lunch in which participants from both sessions could share a meal with the research team. The meal included country food prepared by Inuit community members. *Country food* refers to traditional Inuit food, usually containing game meat, fish and marine animals, birds, roots, and berries. This food is an important part of Inuit cultural identity and is considered a spiritual link between Inuit and the land [33].

In addition to focus groups, seven semi-structured interviews were conducted with health service providers who had experience caring for Inuit with cancer in the urban area. Our sample included nurses, physicians, managers, and allied health professionals and they were recruited by our partner organisations using snowball sampling. We posed questions that probed for their experiences with the provisions of cancer care, and barriers and facilitators to providing culturally safe care for Inuit.

#### Data analysis

Audio recordings of the focus group discussions and semi-structured interviews were transcribed verbatim, de-identified, and entered into NVIVO 12 software [34] to facilitate analysis. We used an inductive thematic content analysis to analyse the data for themes related to the research objectives [35,36]. Two research associates (DR; ZA) read the transcripts multiple times and developed general codes using the participants' own words to highlight meaningful segments of the data. Following this initial review, a codebook of the general codes and representative guotes was reviewed together by all coauthors (Inuit and Western research partners) in frequent face-to-face meetings to facilitate shared understandings and meanings, and resolve any discrepancies. Themes were inductively co-developed through an iterative process of data display, re-coding, and reducing codes as they related to the research objectives, prioritising understandings and interpretations by the Inuit partners to ensure that the results were firmly grounded in an Inuit

Table 1. Demographic data of participants

perspective. Thematic saturation was reached when no new codes or themes emerged from the data [37].

#### **Ethical considerations**

This research study was reviewed and approved by the University of Ottawa Research Ethics Board (#H-06-18-787). We additionally took guidance from Chapter nine of the Canadian Tri-Council Policy statement on research involving First Nations, Inuit, and Métis Peoples [27] and the National Inuit Strateav on Research [24]. Recognising and respecting the importance of traditional cultural values, community engagement, and trusting relationships, we honoured practices within the National Inuit Strategy on Research, including: pre-research consultations and relaapproaches, tionship building, community-specific research possession agreements, confidentiality, and informed consent.

#### Results

A total of 28 cancer survivors and family members participated in the two focus group meetings and 7 healthcare providers participated in an individual interview, for a total of 35 study participants. Sixty-eight percent of cancer survivors and family members were female as were 100% of healthcare providers. In the focus group meetings, all participants were lnuit except for one male who stated he was non-lnuit but attended with his wife who was lnuit. Healthcare providers included physicians, nurses, medical interpreters, case managers and coordinators. Three of the seven (43%) healthcare providers who participated in an interview identified as lnuit and a fourth married into an lnuit family. See Table 1.

Three key themes emerged to describe the meaning of culturally safe cancer survivorship care to Inuit: 1) access to traditional ways of life, 2) communication, and 3) family involvement. Subthemes were embedded within these key themes that included: country food; traditional practices; language and translation of knowledge; non-verbal communication; and health systems, care processes and delivery (See Table 2). Salient barriers were identified for Inuit to experience culturally

	Focus Groups n=28	Interviews n=7	Total n=35
Inuit	n=27 (96%)	n=3 (43%)	n=30 (86%)
Female	n=19 (68%)	n=7 (100%)	n=26 (74%)
Age Range			
19-40 years	n=6	n=1 (14%)	n=7 (20%)
41-60 years	n=13	n=4 (57%)	n=17 (48.5%)
>61 years	n=8	n=0 (0%)	n=8 (23%)
missing	n=1	n=2 (29%)	n=3 (8.5%)

\* one person in the focus groups and one person in the interviews did not identify as lnuit but married into an lnuit family/community.

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#### Table 2. Meaning of culturally safe care for inuit.

#### Theme & Subthemes

- 1. Access to Traditional Ways of Life
- Country Food
- Traditional Practices
- 2. Communication
- Language and translation of knowledge
- Non-verbal Communication
- Health Systems, Care Processes and Delivery

3. Family Involvement

safe care with costs and limited resources being central to all the themes. Participants made suggestions to improve the delivery of culturally safe care with immediate and long-term actionable items discussed.

#### Culturally safe cancer survivorship care

#### Theme 1: access to traditional ways of life

All participants discussed feelings of decontextualization and acculturation when accessing cancer treatments outside of their home communities, which were frequently remote communities across lnuit Nunangat. Participants identified country food and traditional practices as essential aspects of culturally safe care. They also discussed how barriers to these activities and practices had a negative impact on their mental health and overall wellbeing.

#### **Country food**

Participants stressed the cultural importance of country food for overall wellbeing and healing. However, in an urban setting, the cost and availability of country food made it difficult for many patients and families to obtain:

And the people who have been here for a long time, their spirit[s] are so down because maybe not enough country food or something. Part of our tradition is that when we welcome anybody or want to help anybody, we offer food because it brightens somebody's day. (Focus Group Participant)

# **Traditional practices**

In addition to country food, the urban setting was described as challenging for Inuit patients and families to participate in traditional activities such as crafting (e.g. beading and carving) and spending time out on the land. However, instances of care that were sensitive to the importance of these practices and the benefits thereof were discussed: He's a carver and he felt like being able to carve would make him feel better. [...] so she [the nurse] found a space within the [hospital] that he was allowed to carve in. And he spent all his free time there and it, it made him happy. It helped him get through it all. (Interview HCP2)

I always use a land-based approach [emphasis added]. I try to get out and about, away from the hospital setting, as much as possible. I feel that's where the most trusting relationships are developed. [...] going out berry-picking, activities like that is important to them. Going goose-hunting, going fishing, going hunting and stuff like that. Those are very important and that can be tied, again, to stress-relief and being connected back to the land. And what I have found in the past very healing is doing art-based activities like beading for example and also sewing. (Interview HCP1)

A few participants discussed spirituality as an aspect of traditional life that is important to many Inuit, and this concept was confirmed by our Inuit research team. As stated by one participant: *"spirituality's big with a lot of Inu[it]"* (Interview HCP5). Before the colonial imposition of Christianity, traditional Inuit customs and practices centred around Inuit principles and values of which relationships are key:

It is a customary practice for Inuit to visit people who are not well, who are sick. That's a custom. Her mother, through her religious beliefs, had to visit other people, so that was her practice because not only religion but also customary to visit people who are not well. (Focus Group Participant)

Participants also discussed obstacles that impacted their ability to access and practice many traditional ways of life. These challenges included accessing country food, being able to partake in crafts, and the forced distances and time that separated the urban centre from their home community:

[...] when my dad was down here for cancer, he couldn't do any crafts, he couldn't do anything really [emphasis added]. But the most important thing that he wanted and needed was being able to have visitors

from family and friends. But being at [location] there's a limit to that. There's certain hours you can only visit and for a couple hours you can't go see your dad. (Focus Group Participant)

They're travelling down from the north, and it's every oncologist's role here to treat cancer. To cure, that is their, their ultimate goal. But a lot of them don't realize that people are leaving their homes, their, their culture, behind to come here for this. [...] And it's chemo every two weeks. That does not leave time in between treatments for someone to travel back home. But after so you know, so many weeks of being here, sometimes it's better for their mental and emotional wellbeing to get back home. They, they, they want that. They want see their family. They want to be in their communities. They want to maybe even get out on the land." (Interview HCP2)

#### Theme 2: communication

Inuit communication was discussed as extending beyond simply words that are spoken to include different forms that should be understood by healthcare providers working with Inuit. Clear communication between patients and their healthcare providers is an essential aspect of cultural safety; clear communication leads to services that are free of racism and discrimination and helps build trust and support providers [38]. To ensure cultural safety, the importance of considering the social, cultural and emotional needs of Inuit patients was affirmed to allow them to draw strengths from their identity, culture and community. Thus, being able to recognise what is being communicated, and being mindful of one's own actions, is essential. In particular, participants discussed challenges with: language and translation of knowledge, non-verbal cues, care processes, and care delivery, as well as health system and/or community-based supports.

#### Language and translation of knowledge

Participants emphasised significant challenges with translating lnuktut languages to English and vice versa. These challenges were compounded by the fact that many lnuit dialects exist. However, written communication was predominately translated into one dialect, lnuktitut, rather than into the unified writing system that is being developed by and for lnuit in Canada [39]. As stated by Interview Participant HCP6:

Inuktitut is a difficult language. There are not always words in Inuktitut that we have in English. So having any type of conversation, whether it's around cancer or prognosis, outcomes, you know, statistics, those are harder concepts for the clients to understand and for us to figure out how to relay that information. But that said, you know, having an interpreter who's familiar with it, it comes into play quite often when we're having conversations around palliative care and end of life, we struggle with finding someone that can interpret this information the right way. (Interview HCP6)

Understandably, the challenges with translating knowledge from Inuktut to English (and vice versa) impacts healthcare providers' ability to convey knowledge and answer questions about cancer care processes, and this also impacts Inuit patients' understanding of their cancer journey. One participant described not knowing what to expect in the cancer journey or what questions to ask to health care providers:

And understand that they might have questions but ... people don't know what they don't know. So, they might have questions but they might not be able to ask them to a nurse that they don't know. [...] I've been to the doctor before and I do have some questions and I'm thinking, well I don't know, because I don't know. I'm not the doctor, I don't know what I should be asking about my own health. And especially if it's cancer, they're not going to know ... (Focus Group Participant)

Some participants discussed using the *My Journey booklets* (*Inuusinni Aqqusaaqtara*) [40] to help them understand their cancer journeys. The *My Journey booklet* provides plain-language definitions, local resources and easy-to-read cancer information in English and regional dialects (Inuktitut, Nunavik, Inuinnagtun):

And I think it's very personal. 'My Journey booklets', this is my first booklet, and it talks about the resources that can be used. There's a lot of languages that we don't understand. And talking about Oncologist, it explains what an Oncologist is, and it explains what a Navigator is. So, it's going into the details of the language that is used when it comes to cancer. When people don't understand what cancer is and they can come to this booklet and it can be a very useful booklet for them and also, the service providers in the different areas like, Ottawa, Montreal, and various providers that can help you. And so this is more of a resource that you can use to learn more about cancer (Focus Group Participant).

#### Non-verbal communication

To create cultural safety, participants emphasised the importance of healthcare providers being aware of the different ways Inuit communicate. Non-verbal cues and actions were described as particularly powerful aspects of Inuit communication styles:

And so I park at the, [redacted location] so when I park there and when you come up from underground parking there's hanging Narwhals and Belugas. So you don't have to say anything. You're with the Inuit from Nunavut, and they're coming up and they're seeing something that they see all the time in their communities, right? So right away it's acknowledging their culture, not saying a word. It's all in the action. It's not even words, it's in your action." (Interview HCP1)

#### Health systems, care processes and delivery

Communication also extended to the ways in which care processes were embedded and enforced within the Western healthcare system. Participants described how colonial practices have reinforced paternalistic and non-inclusive approaches towards health and healthcare for Inuit:

.... when the Europeans came up north, they were in control. And up to today, they're still in control. .... [Inuit] just say, "Yeah, yeah, yeah, okay, okay, okay," Like, no input. If we try to say anything, and they just say "Well, you need this 'cause it helps you," and that's it. Like, nobody's listening to that person [say] "I don't want that," or, "Can that be delayed?" And in the end, they [Inuit] become bitter 'cause they're just listening to the nurses and the doctors. ... . bitter and bitter and bitter. [...] even though medical interventions are good, there's a limit to them. And that limit, when it goes overboard, forcing a cancer patient to endure a lot of unnecessary interventions and causing them more grief, and being down here [in urban setting] longer and away from their family longer, they tend to go downhill faster, and their mental illness goes down faster as well. So ... .once they know that they're gonna pass away, at least give them the time with their family, their community, and all that, it would be nice, rather than just stick them down here and get angry and bitter and resentful. (Interview HCP4)

Participants described Indigenous-based community resources, patient navigators, trauma-informed approaches, and providers' awareness of Inuit culture as important to culturally safe care. In the urban setting where this study was conducted, there were both Inuit and non-Inuit community-based resources dedicated to supporting Inuit patients. A healthcare provider interview participant describes the importance of these resources:

A lot of times with new cancer patients, they need a lot of moral support. That's where [representatives of Inuitbased community support programmes] used to come in, explain about the treatments, or navigate, or be the support for them in regards to medical interventions, or follow-ups for doctors. Or what we used to do up in north, too, is once a week we used to have tea, teahow do I say, tea parties for elders. And they would be included in the program, or they'd just get together and just support each other. There'd be games or they would be eating together once a week and that, to be part of the community. 'Cause when they have cancer, they tend to isolate themselves or just be sick. So [we] try to make sure they're included in the community or make sure what they need or what they're asking for is met so that they're more, they can function" (Interview HCP4).

It was revealed that the major hospital in this urban setting has a patient navigator for cancer care with Indigenous patients and the navigator supports Inuit by helping them navigate the healthcare system and access traditional ways of life:

If you could work with a health systems navigator [for Indigenous patients], get some supplies, order country food, that's one place you can go and like in my program this is what I do. You can do the same thing with the Inuit facilitator with the hospital and it's easy to do. (Focus Group Participant)

In summary, the importance of engaging with Inuit and showing a respectful interest in understanding their culture, history, and experiences is of paramount importance to providing culturally safe care. Given the importance of recognising the intergenerational trauma that has resulted from colonialism, participants discussed the importance of both the Truth and Reconciliation Commission of Canada: Calls to Action [41] and using trauma-informed approaches:

Well, certainly better understanding of the culture, understanding the recommendations from the Truth and Reconciliation Calls to Action. Improved knowledge about the— you know, understanding that there's other comorbidities often, you know, such as ... they, they've all experienced death from either chronic illness or suicide or, you know, horrible [...]. There's not enough Inuit professionals in healthcare up there. There should be better cultural competency, especially in all healthcare providers in the south, nurses, and up in the north. (Interview HCP5)

#### Theme 3: family involvement

Participants described how family relationships are an essential aspect of Inuit culture and discussed how an Inuit understanding of family is different than non-Inuit:

They already have the family support or the community support already because that's how we were brought up, to support each other, through hardship or death in the family or whatever. It's a community thing. It's not individualized like it is down here, like, everybody's alone down here. Up north everybody's together. (Interview HCP4)

Building on the theme of family involvement, participants described how the impact of an illness affects not only the patient, but the entire community:

Well when someone is diagnosed with cancer, it's not just that person who's affected. Immediate family members are affected in a huge way and your distant families too are affected. That in turn affects the whole community. (Interview HCP7)

Often coming thousands of kilometres from their homes to access cancer care in urban settings, transportation for family members was discussed as posing significant challenges. Participants spoke of medical travel policies that only pay travel expenses for one person to accompany a patient on medical travel. Thus, family members wishing to escort cancer survivors while undergoing treatments face prohibitive costs for travel, loss of income and additional burdens on their families when they are away for extensive periods of time::

[...] when you agree to come down here as an escort for any patient who's down under medical travel, you're agreeing to be here for four weeks. So not everyone can leave their home life for four weeks. [...]. And some of them have young children that they're leaving behind. They're also leaving their jobs behind. And this is unpaid leave that they're on, [...] that is another barrier for some people in how they can manage that. Even though they want to be with their, their loved one. (Interview HCP2)

Within urban settings, the involvement of family and friends in patients' care was limited by strict visitation policies:

[...] from what I've seen in the certain hospitals, they have a very high limitation of the number of visitors that the patient can receive. And I can understand that it's to protect the patient from being overwhelmed and having that proper rest time. But I think it's also very important to know that family is indeed a big support for the Inuit patients. (Interview HCP6)

#### Barriers for inuit to experience culturally safe care

#### Costs and limited resources

As stated by Interview Participant HCP4, *"it always comes down to financial"*. Through the course of the focus groups and interviews, costs and limited resources continually emerged as an overarching obstacle for Inuit cancer survivors to receive culturally safe care in an urban setting and finances impacted the patient, family, and community organisations. Placing the financial burden of travel on individuals to support their loved ones undergoing treatments in urban centres was seen as an assertion of Western values that fractures services and do not uphold the autonomy of Inuit for culturally safe care:

Well the barriers are, are the Government of Nunavut medical travel policy, and the escort policy, is just and I understand there needs to be fiscal responsibility and we can't just have everybody's entire family down here, unfortunately. I think it would be nice for them but there's just— it just costs way too much money, so that policy is in place to protect that. And so it's definitely a barrier in, in getting [the family] down here. (Interview HCP2)

So money's always a thing, right? Budget, budget, budget. And then, because it's a budget, I feel there's too much disconnect between all the organizations who support the Inuit. You know, there's different organizations within [urban setting], they might not get along. But we just need someone who's more patient-centred. Not organizational-centred, not trying to get the best for the place that they work. (Interview HCP1)

# Suggestions to improve the delivery of culturally safe care

Although not explicitly asked, participants had suggestions for improving the delivery of culturally safe cancer care for Inuit in urban centres. Predominantly, the calls to action within the Truth and Reconciliation Commission must be responded to, engaged with, and implemented in the Canadian healthcare system to redress the legacy of colonisation and advance culturally safe care delivery for Inuit and Indigenous patients. Immediately actionable items discussed by participants were: providing access to country food, providing traditional crafting supplies, designated spaces where families can commune and support one another, and involving families that are not present in the urban setting through phone call updates and virtual family meetings. Of note, all participants mentioned providing bus tickets for patients and families to visit one another:

If the, if the family members that live down here are given bus tickets to visit their family members that are in the hospital or at [redacted community organization] while they're down here. That would help the patient a lot. [...] Because they, they have family coming in to meet, to meet with them, talk with them, comfort them, hold them, things that they would not have gotten otherwise. [...] It, it shows them that somebody cares. That they're not gonna die alone. (Interview HCP3)

In addition, the potential to expand the role of the patient navigators was discussed. This could include a team of different healthcare professionals to support Inuit holistically, rather than one Registered Nurse (as was the circumstance in the urban setting where the study was conducted). Participants suggested including different disciplines in the navigation team, such as nurses, interpreters, dietetics, and social work:

I would bring in a social worker one time 'cause people don't have ... they don't do up wills or they don't know how to do their ... like when you're on extended leave from work, the paperwork for that. So it would be nice to have a social worker come in and talk to all of them, go over all these things .... (Interview HCP2).

I'm back to a dietician, about country food. [...]. A dietician would be there for what kind of vitamins is most important depending on which part, spot was diagnosed and then what vitamins are good for it. Those are the things that would be very helpful for a patient. (Focus Group Participant)

## Discussion

The purpose of this study was to explore both the meaning of culturally safe cancer survivorship care and the barriers and facilitators to receiving that care for Inuit in an urban setting in Ontario. Our results support that there is a state of aporia with respect to the delivery of culturally appropriate cancer care for Inuit. The term *aporia* denotes an impasse that emerges when two compelling approaches, or perspectives, are incommensurate and we are unsure about how to proceed [42]. In the last decade, there has been an increased impetus to conduct research with Indigenous/Inuit communities [43]. These research efforts have explored culturally safe care for Inuit and multiple models and initiatives have been developed [21,44-47]. However, despite these efforts, participants in our study described significantly more barriers than facilitators to culturally safe care and discussed ongoing feelings of paternalism in the current healthcare approaches. This contradiction between current efforts and the actual experiences of Inuit patients and families suggests the need for more radical or comprehensive change in how we conceptualise and deliver care with these populations.

Most studies to date have taken an illness-based empiric approach, comparing quantitative metrics related to Inuit cancer survivorship with similar metrics for non-Inuit (or non-Indigenous) populations such as rates of cancer [48], "potential years lost" [49], comorbidities [50], and "risk factors" [51]. Other studies have explored reasons Inuit patients do not comply with cancer screening recommendations and treatments [52], emphasising Western conceptions of one's personal responsibility for their health [53]. There is no doubt a need to provide biomedically-based curative treatments and care, and while this is certainly valuable knowledge, it does little to actually address or engage with the social determinants of Inuit health [54]. This categorisation and comparison of Inuit populations with non-Indigenous populations reinforces hierarchical settler-colonial conceptualisations that Indigenous populations must be brought towards the norm of the primarily white urban Western populations [22].

This study was conducted as a partnership between the University of Ottawa and Pauktuutit Inuit Women of Canada (www.pauktuutit.ca), a national organisation with strong community links and recognised leader in strength-based community research grounded in Inuit perspectives [3,45]. Through the support and trust provided through this partnership, Inuit participants were able to describe their perspectives and experiences in their own words. Guided by Inuit values and Nunavutspecific IQ [29], participants described their experiences without the spectre of settler-colonial interpretations and identified significant concerns with accessing traditional ways of life, communication, family involvement, geographic distance, and finances.

Culturally safe care strives to honour the distinct cultural identity of Inuit. A key part of Inuit cultural identity are traditional ways of life such as country food and traditional medicines, crafts, and access to the land [45]. In addition, Inuktut can be an expression of cultural identity and understood to be more than a language; Inuit culture is often embedded within the language itself [46]. It follows that Inuit Tapiriit Kanatami (2014), the national representational organisation protecting and advancing the rights and interests of Inuit in Canada [55], identifies language as one of the social determinants of Inuit health. Participants discussed challenges with accessing resources in Inuktut, lack of Inuktut translators when accessing and lack of Inuit healthcare providers. care, Participants spoke favourably about the cancer resources developed by Pauktuutit, specifically Inuusinni Aggusaagtara (My Journey) booklet which was developed with the Canadian Cancer Society [40], and the Kaggutig Inuit Cancer Glossary developed with the Public Health Agency of Canada [56]. These resources provide plain-language information about cancer in English and different dialects of Inuktut and seek to build cancer literacy among Inuit in a culturally responsive and appropriate way.

While participants in our study were aware of resource constraints, finances and geographic distance were among their prominent concerns. With three quarters of Inuit living in Inuit Nunangat across northern Canada, Inuit often travel at least 2000 kilometres from their home communities to receive treatments and care in urban centres [44,49]. While the literature identifies this distance as a barrier to cancer care, it is described as a risk factor for delayed diagnosis and treatment [57]. For participants in this study, distance had a more profound meaning. It represented extended isolation from their families and community, a loss of income, and, at times, an interruption in the grief process, with many Inuit not given an informed choice

about the full implications of leaving their communities to seek care. For family members in home communities, the cost of travelling is exorbitant, and many are unable to leave their responsibilities at home for months at a time. The lack of adequate subsidies or compensation schemes maintain an oppressive colonial imposition within the health and political systems, as it prioritises the treatment of cancer over the provision of culturally safe and holistic family-centred care. While many lnuit patients prefer care in their own communities [45,58], this opportunity is very limited by the lack of infrastructure and funding, limited training and recruitment of lnuit healthcare professionals, and an overall lack of political will [54].

As described by participants, placing the financial burden of travel to access care on Inuit is an example of the ongoing colonial practices in our health system. Austerity measures in the name of fiscal responsibility has been shown to disproportionately impacts vulnerable populations [59–61] and, as ascertained by Indigenous scholar Coulthard (2014) ascertains that "the conflict at the heart of those power relations effaced by the liberal recognition paradigm is primarily economic in origin" (62, p.51). The fracturing of services, in light of financial restraints such as restrictive travel mandates, creates further obstacles to creating holistic and culturally safe care.

Our findings are similar to two recent studies conducted with the same population [45,63], suggesting that, despite laudable efforts, the concerns and experiences of Inuit are widespread and there has been little improvement in the delivery of culturally safe care (i.e. state of aporia). Recognising this trend lends further support to our assertion that Western healthcare delivery is not responsive to the needs and realities of Inuit. Within the framework of the United Nations Declaration on the Rights of Indigenous Peoples [64], Wilmot [65] argues that the right to culturally appropriate healthcare, enshrined in the UN Declaration (Article 24), has not been adequately recognised in Canada. The problem, according to Coulthard [62], is that "the [Truth and Reconciliation Commission] temporally situates the harms of settler-colonialism in the past [...]. Indigenous subjects are the primary objects of repair, not the colonial relationship". (p. 127). We assert this parallel within the healthcare system, where Western perceptions of health as a personal responsibility view Inuit behaviours and concerns as things to "repair", and not the system itself.

The discrepancy between Inuit and Western ways and values is also reflected in research methodologies. Healy & Tagak [21] have identified that although novel research approaches have sought to involve Inuit

patients, such as participatory action research, these approaches are still fundamentally grounded in Western ideologies and epistemologies. A recent systematic review on cancer survivorship interventions utilised among Indigenous people found studies predominately used research methodologies that do not represent Indigenous approaches to knowledge development [66]. For example, a study with American Indian and Alaska Natives reported that participants were not receptive to the survey as a form of data collection, however they positively engaged with the arts based intervention [67]. While researchers attempt to identify and measure correlates of Inuit and Indigenous health, many empiric studies continue to disregard that this approach is incompatible with Indigenous or Inuit lifeways and allows Western values to continue to permeate health discourses [22]. As stated by Kovach (2009), fundamental ontological and epistemological differences exist between Western approaches and Indigenous knowledge: "Western science in particular has worked to first subjugate and then discredit Indigenous knowledge systems and the people themselves" (p. 77).

In order to move forward, Fijal and Beagan [68] recommend approaches such as Two-Eyed Seeing that brings together both Indigenous and non-Indigenous perspectives in health research. Two-Eyed Seeing is an approach that has been articulated by Mi'kmag Elder Albert Marshall, and although not specific to Inuit, the concept of balance between Western science and Indigenous Ways of Knowing, which are unique to each community, provides a starting point for Western researchers to explore different epistemologies and methodologies. Accordingly, researchers have started to use various Inuit epistemologies to guide their research. Our study was informed by the Nunavut-specific IQ epistemology, which, translated to English means "that which Inuit have always known to be true" [29]. However, we did broaden our epistemological lens to include Inuit principles that guide Inuit communities across the other three land claim regions in Inuit Nunangat. Like other Indigenous knowledge systems, IQ is recognised as "a unified system of beliefs and knowledge characteristic of the Inuit culture" [29]. The IQ epistemology is underpinned by four big laws, or maligait, that have been adopted by the government of Nunavut and include: 1) working for common good; 2) respecting all living things; 3) maintaining harmony and balance; and 4) continually planning and preparing for the future [29]. Guiding principles include adopting an IQ approach in research and honouring IQ guiding principles, which include consensus decision making,

working together for a common purpose, and environmental stewardship being necessary to sustain Inuit traditional knowledge, helps Inuit reclaim their ways of being well [29].

In a study about Inuit patients and families' experiences of cancer care, Galloway et al. [45] used the Pilirigatigiinnig Model for Community Health Research developed by Healy & Tagak Sr [21], to guide the conduct of their study and their data analysis. The Pilirigatigiinnig Model is underpinned by 5 core Inuit concepts and emphasises collaborative knowledge production, reflecting the relational nature of Inuit Ways of Knowing. Further still, Ferrazzi et al. [69] describe the Aajiiqatiqiinqniq consensus approach, one of the IQ guiding principles, as a "wholly Inuit research methodology" (p. 3). In this approach, data is analysed in conventional Western gualitative approaches (i.e. content/thematic analysis and discourse analysis) in conjunction with an Inuit comprehension and analysis of both the conduct of data collection and the results [69]. Through the process of Aajiigatigiingnig, critical reflective dialogue brings these two conceptualisations together through consensus [69].

Qualitative approaches to knowledge-gathering, such as storytelling, sharing circles, journaling, and unstructured interviews, are all conversational and open-ended, allowing for the flexibility required to accommodate Inuit oral traditions [22]. As "policy and programming grow out of research" (22, p13), future research with Inuit should use Inuit epistemologies that honour oral traditions, such as qualitative methodologies. Using these discursive approaches can amplify Inuit perspectives and voices within the academic literature and ultimately contribute to re-orientating political and institutional priorities and policies.

Lack of resources that connect community and hospital services, and inadequate financial supports for families have been identified in First Nations communities in Canada [70,71] and are similar to the barriers identified by Inuit participants in this study. The actionable items recommended by participants focused on using existing resources in new ways. For example, providing crafting supplies and bus tickets would require a marginal reallocation of funds with seemingly major impact. While these recommendations will have immediate impacts on Inuit cancer patients, they are only quick fixes and do not address complex systemic issues. Reticence towards discussing and engaging with issues such as funding, institutional and political reforms perpetuates colonialism within the healthcare system and the delivery of care. To adopt a *de*colonial approach, Inuit ways of knowing must not simply be considered, but must be the locus from which healthcare services are developed and delivered. We assert that colonial Western practices must be actively identified and expunged as efforts to improve a system that is fundamentally steeped in systemic racism perpetuates a colonial approach to health and wellness [72]. Rather than providing small tokenistic actions, we have an ethical responsibility to act on the calls to action within the *Truth and Reconciliation Commission of Canada* that refer explicitly to Indigenous health [41] and actively engage in culturally safe processes to radically reform and realign healthcare to be comprehensively culturally safe.

While realignment of the healthcare system will require difficult conversations and strong advocacy, as healthcare providers, administrators, and researchers, we must strive to communicate cultural safety through actions and relationships that include the how and why, not just through words. To this end, we must not see colonialism as a thing of the past but as an ongoing process that is enshrined in our continued commitments to Western approaches in both health research and Inuit healthcare delivery. One way to move forward is to move through the historical colonial power relations, and commit to reducing the harms of ongoing colonialism and systemic racism and extricate it from current practices [73]. The extent to which settler colonialism, systematic and scientific racism are embedded in healthcare discourses, research, and practices is particularly well hidden [73]. While extricating systemic racism is not something that can be accomplished hastily, working together as Inuit and Western researchers under the principals of IQ allows us to explicitly identify the gaps in culturally safe care so we can deconstruct, reimagine, and co-create something new.

#### Limitations and strengths of the study

The present study was part of a larger research project to develop and implement culturally safe cancer survivorship support for Inuit and First Nations Peoples in urban settings. Limitations include the reliance on an urban sample that may have lacked representation from all regions of Inuit Nunangat and not collecting detailed demographic information on participants' ancestral roots or socioeconomic status. Thus, it is possible that the information shared may vary based on the different geographic regions Inuit in urban settings have come from. Moreover, although our study was developed and conducted in partnership with Inuit and Inuit-based organisations, it was conducted through a Western research paradigm and methodology. The strengths are that we privileged Inuit epistemologies and knowledge in the development of the study design, analysis, and interpretations of findings.

# Conclusion

The geographic remoteness of Inuit communities requires Inuit to travel vast distances to urban centres to receive cancer care. Once they arrive, they are subjected to systemic racism resulting from the legacy of colonialism within the Canadian healthcare system and thus denied the experiences of culturally safe care. However, participants in our study clearly described what culturally safe care in urban settings means to them, with access to traditional ways of life, communication, and family involvement being key aspects. To further understand how to transform healthcare to be culturally safe, studies underpinned by Inuit epistemology, values, and principles are required.

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No potential conflict of interest was reported by the author(s).

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## **Geolocation information**

45.3737°N, 75.7792°W

#### Data availability statement

The data from this study are owned by participants and held in trust by the researchers and *Pauktuutit Inuit Women of Canada*. They are not publicly available.

https://www.pauktuutit.ca/

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