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Research

A qualitative exploration of Indigenous patients' experiences of racism and perspectives on improving cultural safety within health care

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Abstract

Background: In Canada, Indigenous Peoples continue to experience persistent health inequities, resulting in disproportionately poorer health outcomes compared with non-Indigenous Canadians. This study engaged Indigenous patients accessing health care in Vancouver, Canada, about their experiences of racism and improving cultural safety within health care.

Methods: A research team consisting of Indigenous and non-Indigenous researchers committed to employing a Two-Eyed Seeing approach and conducting culturally safe research hosted 2 sharing circles in May 2019 with Indigenous people recruited from urban health care settings. Talking circles were led by Indigenous Elders, and thematic analysis was used to identify overarching themes.

Results: A total of 26 participants attended 2 sharing circles, which included 25 self-identifying women and 1 self-identifying man. Thematic analysis resulted in the identification of 2 major themes: negative experiences in health care and perspectives on promising health care practices. For the first major theme, subthemes included the following: experiences of racism lead to poorer care experiences and health outcomes, Indigenous-specific racism results in mistrust in the health care system, and participants experience discrediting of traditional medicine and Indigenous perspectives on health. For the second major theme, subthemes included the following: Indigenous-specific services and supports improve trust in health care, Indigenous cultural safety education is necessary for all health care–involved staff, and providing welcoming, Indigenized spaces for Indigenous patients encourages health care engagement.

Interpretation: Despite participants' racist health care experiences, receiving culturally safe care was credited with improving trust in the health care system and well-being. The continued expansion of Indigenous cultural safety education, the creation of welcoming spaces, recruitment of Indigenous staff, and Indigenous self-determination over health care services can improve Indigenous patients' health care experiences.

Globally, Indigenous Peoples have a shared history of colonization occupation and dispossession, which is acknowledged in the United Nations Declaration on the Rights of Indigenous Peoples.[1] In Canada, this has contributed to important health gaps between Indigenous Peoples and non-Indigenous populations, where evidence indicates that Indigenous Peoples have an increased disease burden, have poorer health outcomes and are less likely to access health care services in comparison to non-Indigenous populations.[2–9] This includes among First Nations people, who have inhabited North America before European colonization and since time immemorial;[10] the Inuit, who are the first peoples to inhabit the Arctic region of North America since time immemorial;[11] and the Métis, who are a distinct Indigenous group originating from the Red River and Saskatchewan River settlements in Manitoba, with settlements now found in other regions of western Canada.[12] These inequities are a direct outcome of colonization and the complicity of health care systems in medical colonialism, which have systematically and intentionally disrupted Indigenous Peoples' way of being and knowing through cultural genocide, the forceful removal of Indigenous Peoples from their lands, and the imposition of Eurocentric perspectives on health.[13]

In British Columbia, where this study is situated, recent evidence has attributed persistent health inequities and health care aversion among Indigenous Peoples to widespread anti-Indigenous racism within BC's health care system. This has been extensively documented in the government-commissioned report that followed the present study, *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination*

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in BC Health Care,[14] commissioned by the BC minister of health, which recommended hardwiring Indigenous cultural safety throughout BC's health care system and recognized the importance of Indigenous self-determination over health care. This is reiterated in the *Declaration on the Rights of Indigenous Peoples Act* Action Plan: 2022–2027,[15] which commits the provincial government to abiding by the United Nations Declaration on the Rights of Indigenous Peoples and working to eliminate all Indigenous-specific racism in the health care system.

To date, evidence has examined the impacts of Indigenous-specific racism on Indigenous Peoples' health care access, experiences and outcomes,[4,16–22] though existing research from Vancouver is specific to Indigenous Peoples with substance use disorders,[16] accessing hospital-based services[18] and accessing services in Vancouver's inner city.[20] Despite this, there is limited research from urban settings in BC on experiences of anti-Indigenous racism in health care and Indigenous Peoples' perspectives on culturally safe health care. Driven by existing calls to action and recommendations, the Vancouver Coastal Health Indigenous Health department initiated this study to hear and centre Indigenous Peoples' voices and directly inform health care system transformation.[23] Therefore, given existing knowledge gaps, we sought to better understand the health care experiences and perspectives on culturally safe health care practices among Indigenous Peoples.

Methods

This qualitative study was conducted by an Indigenous-led research team committed to culturally safe research on the ancestral, occupied territories of the Musqueam, Squamish and Tsleil-Waututh Peoples in what is now referred to as Vancouver, BC. We used a Two-Eyed Seeing approach and a sharing circle methodology to explore Indigenous Peoples' experiences of racism in health care and perspectives on culturally safe health care. Two-Eyed Seeing is a theoretical framework coined by Mi'kmaq Elder Albert Marshall in the context of health research that acknowledges and upholds the importance of both Indigenous and Western epistemology[24–26] (Appendix 1, available at www.cmajopen.ca/content/11/3/E404/suppl/DC1).

A sharing circle methodology is a traditional means of relational knowledge sharing and exchange used by some Indigenous communities in North America, which has been previously used in health care research.[27–30] As all participants in sharing circles are considered equal, this methodology disrupts power dynamics and contributes to creating a safe space for discussion and storytelling.[28,30–34] Two sharing circles were conducted in May 2019, 1 led by Elder D.F. and another by Elder R.P., which were held in 2 locations that were purposefully designed to be culturally safe. The sharing circle discussion guide (Box 1) was developed by the research team in accordance with the patient-centred accessibility framework[35] and under the guidance of Elders D.F. and R.P. and the leadership of B.B. Whereas all facilitators self-identify as Indigenous, non-Indigenous research team members participated in the sharing circles, and all team members were encouraged to reflect on their positionality before the commencement of the circles. Additionally, each team member maintained notes on personal reflections and thoughts, which guided the analysis and interpretation of findings.

Box 1: Talking circle question guide

Q1: Based on your personal health care experiences, what are some specific areas within the health care system that need to change for Indigenous Peoples?

Q2: What can researchers and people within the health care system do to support Indigenous Peoples? What can be done to lift Indigenous Peoples up and improve their health? Can you think of a good experience that you had, with a doctor, a nurse, in a clinic or a hospital setting that we can share with health care providers and researchers?

Participants

To be eligible for inclusion in this study, participants were required to self-identify as Indigenous; have accessed health care services within the urban regions of Vancouver Coastal Health, including the municipalities of Vancouver, Richmond, North Vancouver and West Vancouver; be older than 18 years of age; and be able to provide informed consent. A convenience sampling approach was used to recruit participants by word of mouth, placing posters in health service centres frequented by Indigenous patients, and through community partnerships held by Vancouver Coastal Health Indigenous Health Department. Additionally, the research team shared a meal with participants before the start of the sharing circle, and participants were provided with a $25 honorarium in appreciation for their time.

Data collection

The consent form was reviewed and informed consent was obtained before the commencement of the sharing circles. Each sharing circle began with a traditional welcoming from the Elders, followed by a round of introductions in which all participants, including research team members, had the opportunity to situate themselves and reflect on their positionality. Following a conversation about the expectation of the circles, coauthor B.B. began asking questions from the question guide that were purposefully broad to explore participants' historical experiences of racism in health care and perspectives on cultural safety in health care. The cultural safety of the circles was supported by readily available counselling services and Elder support, as well as providing time and space for prayer, ceremony and healing through traditional medicines.

Each talking circle lasted about 2.5 hours and was audio recorded and transcribed. Transcripts were then reviewed by A.P. and S.F. for clarity and to remove any identifying information to protect participant confidentiality. Further details on the procedures of the sharing circle are presented in Appendix 2, available at www.cmajopen.ca/content/11/3/E404/suppl/DC1.

Data analysis

Thematic analysis was conducted by coauthors A.P. and S.F. This involved developing an initial codebook by hand, which began with the identification of broad themes that were subsequently refined through the inclusion of additional quotations.[36] Any discrepancies in coding or thematic categories were resolved through discussion and consensus, and coauthor B.B. was consulted in instances of disagreement until consensus could be reached. Data analysis was guided by the patient-centred accessibility framework.[35] More specifically, we sought to characterize patients' access to health care and resulting experiences, with the intent of providing insight into factors that influence patients' health care access. This framework was considered throughout thematic analysis and guided the identification of the major themes and subthemes.

Ethics approval

Ethics approval for this study was received from the University of British Columbia Research Ethics Board (H18-03565).

Results

Two talking circles were conducted, with 16 in the first sharing circle and 10 in the second, for a total of 26 participants. Twenty-five participants self-identified as women, and 1 self-identified as a man. Most participants were adults older than 24 years ($n = 24$). Two major thematic areas emerged, the first highlighting participants' experiences of racism in health care and the second sharing participants' perspectives on promising health care practices.

Experiences of racism in health care

Experiences of racism lead to poorer care experiences and health outcomes

Racism, prejudice and stereotypes were commonly reported by participants, with many sharing experiences that resulted in their feeling devalued, disrespected and abandoned (Box 2). Participants discussed situations in which stereotypical inferences were made that affected their health and found that disclosing their personal history sometimes resulted in being treated poorly. As 1 participant noted, disclosing that they attended residential school immediately changed the dynamic of the relationship with their physician in a negative way. In other instances, participants described how stereotypes about substance use within Indigenous communities resulted in their being labelled as "drug-seeking," how their safety was ignored and examples of how they were provided with substandard treatment because they were Indigenous.

Box 2: Experiences of racism lead to poorer care experiences and health outcomes

"As soon as [my doctor] found out I was a residential school survivor, she didn't like me. She damaged my insides from a rough, careless pap smear."

"So many in the medical profession look at us like we are a number, look at us like we're not people. We're either completely invisible and get forgotten about or get on the receiving end of abuse."

"I was in a car accident and I went to the emergency. The doctor wouldn't even touch me. He wouldn't even check me physically. What he said to me was, "Ordinarily, I would prescribe you some T3s [Tylenol with codeine #3], because that's what you want." And I said, "No, I want to discuss pain relief. I'm allergic to pain relievers and I take my own medicines.""

"I suffered such bad physical violence, and so my partner kept me from going to hospital. But when I did get to the hospital, they told me I had to deliver [my baby] by myself. And they put me across from a lady who was giving birth and my baby passed away. And when police came and I was so badly beaten, they wouldn't help me. And when I went to the hospital the nurses would treat me so poorly, they would stitch me without anesthetic."

"Once, [the specialist physician] was talking about residential school and he told me 'why don't you just get over it?' I was explaining to him how much body pain I was experiencing … and he charged right at me and grabbed me and said, 'What is this? … That's skin and we all have it. You need to toughen up!'"

Indigenous-specific racism results in mistrust in the health care system

The plethora of negative experiences shared by participants is highly problematic, but it is also concerning that these instances of discrimination negatively affected participants' views toward health care services and their overall health (Box 3). For many participants, this abuse of power and mistreatment resulted in resentment and anger toward health care providers and the health care system, while others expressed fear of the health care system and feeling coerced into treatment. Some participants also described how the discrimination they experienced contributed to their doubt in the intentions of the health care system, which added to a growing sense of distrust in the providers and services they receive. These experiences further entrenched participants' already skeptical views of the health care system, resulting in patients feeling alienated and ignored when accessing health care services.

Box 3: Indigenous-specific racism results in mistrust in the health care system

"Of all the pain, it's pretty obvious they're just waiting for us to die. And because Canada is a colony, the survivors are the most [likely] to experience the health care system. We can go decades in horrendous conditions, and you go to get help, and you think the help is there, but it's not. It's very racist."

"I was in fear of getting older and being Indigenous in Canada — there was a lady who was being screamed at, they were shortchanging her — nobody has done anything, or tried to fix this."

"I'm told that if I don't take the medication, I will be cut financially. And so I'm told I have to take it, otherwise I fear they will come and take my grandchildren away. So I do it!"

"If we have any medical issue, and we got to get help, we don't get it — we get to see all the other [settlers] getting great help, but not us."

Participants experience the discrediting of traditional medicine and Indigenous perspectives on health

Participants also shared their disappointment in many Western health care providers' dismissiveness of the importance of culture, ceremony and traditional knowledge on their healing journey (Box 4). Participants explained that holistic approaches to health and well-being are reinforced by traditional knowledge, but that the incorporation of traditional healing within Western health care settings is often frowned on and seen as ineffective. Similarly, participants described how the Indigenous-specific health care services, including the urban Indigenous health clinic where many participants were accessing health care services, were also seen as "lesser than" Western health care services.

Additionally, some participants shared their frustration that the health care system discredits the importance of kinship ties within Indigenous communities. Despite the central role of Indigenous women as caregivers within their communities and families, many participants highlighted that Western medicine does not acknowledge the importance of Indigenous matriarchs or the value of kinship ties during treatment, and that the supports that many Indigenous women need to care for their family members are often absent. This can be seen through 1 participant's experience, where they were required to care for their family members without essential supports, including somewhere to sleep. Collectively, the discrediting of traditional knowledge by health care providers, and the health care system more broadly, made participants' feel that their perspectives and beliefs were being ignored, reinforcing their distrust in non-Indigenous health care providers and the mainstream health care system.

Box 4: Participants experience discrediting of traditional medicine and Indigenous perspectives on health

"Although [the doctor] thought I couldn't work and I wouldn't be able to accomplish my goals, I started to gain tools from my Elders and support team. I put a care plan in place and the pain started to lift up, through ceremony, through sweat lodge, through drumming, singing songs, being around my sisters and Elders. I have 1 more meeting with [my doctor] and he's going to get an earful. Every time I visit him, he wonders how am I doing this, how am I staying this strong without the medicine? We need to raise the bar!"

"I had to learn how to do physio[therapy], pull catheters and look at stool to see if [they] needed more enzymes. We lived in the hospital for 8 months and they wouldn't even give me a cot to sleep on. I slept on the floor. I wasn't even allowed to eat there because I wasn't a patient … I was responsible for all of [their] care, and got no support at all … . The supports that need to be integrated into the hospitals for Aboriginal women are long overdue."

"When I got into a car accident, I was sent to get x-rays for my neck. The emergency doctor took the letter [from the urban Indigenous health clinic] and chucked it as if it was irrelevant. It's analogous to when you go to [an Indigenous postsecondary institution] and its seen as 'lesser than a regular degree' … I've sent 4 letters from [the urban Indigenous health clinic] to [my insurance provider] and they've ignored all 4. And so, it's not just us being ignored on the individual level, but on the organizational/systemic level as well."

Perspectives on promising health care practices

Indigenous-specific services and supports improve trust in health care

Another important finding was that patients who had accessed services at an urban Indigenous health clinic in the study setting described feeling a stronger sense of trust in their health care providers (Box 5). For participants who struggled with accessing health services in the past, the aforementioned urban Indigenous health clinic represented one of the first times they felt that they had received dignified and considerate care. By placing equal weight on the importance of traditional healing and Western medicine, health care providers at this urban Indigenous health clinic took a holistic approach to patients' health and well-being. Additionally, this clinic provided supports and services not typically available within other clinics. For example, a participant experiencing homelessness described how the staff not only worked to address their health concerns, but also assisted them with securing housing. In another example, a participant discussed their appreciation for how a health care provider intervened on their behalf following a negative experience with a specialist physician they had been referred to, which made them feel safer when accessing care and confident that their health concerns would be addressed in a meaningful way.

Box 5: Indigenous-specific services and supports improve trust in health care

"I was so at the end of my rope with the medical system and didn't want anything to do with it. [This urban Indigenous health clinic] is an entirely different thing; they have a healing room, they have Elders, they have social navigators, they all help, they all care … . And they do even more care, they kind of research the places that are available but also places that hear good feedback about to try to keep your experiences to be good so that you keep on wanting to be well. They really want you to be well, and I've never had that before."

"In [the urban Indigenous health clinic], they also have a social worker. She was the one that my doctor referred me to when I first came to Vancouver, and everyone knows what it's like in this city. And she went out of her way to help me locate the people I needed to find accommodation. I started in a transitional house 'cause I had my grandchildren and I expected to live with them, but that didn't work out. Then I went into 2 shelters, and in the meantime, they were working behind the scenes and secured me housing!"

"[The doctor at the urban Indigenous health clinic] asked me if I wanted her help to intervene with this specialist. I've never had that support before. I've never had a doctor actually listen to me and take a positive action to help me."

"No one gets a number at [the urban Indigenous health clinic]. We appreciate everyone that walks through this door. People tell me it feels like their home, their second home, their family."

Indigenous cultural safety education is necessary for all health care–involved staff

Despite the many negative experiences of and perspectives on health care that were shared, participants also highlighted several positive experiences and ways that health care could be improved for Indigenous Peoples (Box 6). Most patients attested to the value of culturally safe care in improving their health and well-being, and indicated that such education should be mandatory for all health care staff. The positive impacts of culturally safe care can be seen through 1 participant's recollection of an experience they had, where 2 nurses successfully advocated for their family to be present during the passing of their relative. Additionally, several participants shared the importance of hiring Indigenous health care providers to serve Indigenous Peoples. This was seen as an important aspect to rebuilding trust between Indigenous communities and the health care system, that would make many Indigenous people feel more comfortable when accessing health care services.

Box 6: Indigenous cultural safety education is necessary for all health care–involved staff

"If the medical system was actually listening — as part of all orientations [for] emergency, ambulance drivers, front-line workers, mental health workers, for physicians, nurses — they would provide cultural competency training. Part of that is that residential schools is not our legacy, it's their legacy! They need to heal themselves and check the stereotyping of Indigenous residential school survivors."

"For me, the priority should be people-centred medical staff. People understanding people, and I think we are heading in that direction. Many of the students … are taking a cultural safety course at the [medical school]. This should be going out to everyone, even those outside of the [medical school]."

"When we were losing my brother to leukemia, he took a bad fall and he started fading away really fast, and so we all jumped in the car and headed down. What we do is make sure that no one is alone, not even for a minute, there's always somebody there holding their hand. And [the hospital] didn't understand that. The 2 young nurses said they had never seen that before, but we were welcome. And we told them we needed to be there 24/7. The doctors didn't really like it, but the nurses stood by us until the end. There were 2 human beings who understood and respected our wishes."

"If they don't want to do it and provide the care to Indigenous Peoples, then get them out of there and put some Indigenous Peoples in there who are willing to do it, who know what people want."

Providing welcoming, Indigenized spaces for Indigenous patients encourages health care engagement

Participants reported that providing welcoming physical spaces that are inclusive of Indigenous cultures and traditional healing practices encourage health care engagement and contribute to Indigenous patients' well-being (Box 7). Some examples that were presented by participants include providing traditional medicines, smudging supplies and an accommodating space; allowing time for ceremony before or after a consultation; and providing access to Elders and other cultural supports. In 1 example, a participant — despite not being well connected with their culture — described the positive feeling of hearing a drumming circle in the room adjacent to the health clinic while waiting for their appointment. Nevertheless, it was also emphasized that providing welcoming, Indigenized spaces does not compensate for the absence of culturally safe care, and so relationship building was of equal importance to participants.

Box 7: Providing welcoming, Indigenized spaces for Indigenous patients encourages health care engagement

"What really got me is that I hear that [this urban Indigenous health clinic] is for First Nations Peoples, and I'm not by any means traditional, but I was impressed by the do-it-yourself medicine pouches they have at the doors … . And every once in a while, I'm waiting to meet the doctor, I hear the drumming from over [in the other room]. And I hear it and I think, 'this is pretty cool, you can come in here, and you totally feel relaxed, and you totally feel like you belong.'"

"They need to update the [operating room] too! I used to be put asleep at the infirmary and they used to rape me, and that's why every time I get taken to surgery, I start to cry. We need to not have spaces being so sterile."

"It's important to note that by 'Indigenizing space,' we can't expect to get more Indigenous people to attend [health care services] if the connections and relationships aren't already there."

Interpretation

Our findings point to persistent discrimination, prejudice and racism toward Indigenous Peoples accessing health care services in Vancouver. For many Indigenous patients, these experiences resulted in considerable distrust and a lack of willingness to engage in the health care system. Despite these negative experiences, patients shared several examples of ways in which health care services could be improved, including through mandatory Indigenous cultural safety education for health care staff and establishing culturally safe, Indigenous-specific health clinics, which are discussed hereafter.

Although our findings reinforce existing evidence that anti-Indigenous racism is commonplace in BC's health care system,[14,16,20] our results also demonstrate promising practices with the potential to address racism and improve the health care experiences of Indigenous Peoples. One solution that was discussed was the provision of mandatory cultural safety education for all health care staff. More specifically, Indigenous cultural safety education in health care, which was first established in Aotearoa,[37] involves an overview of pre-colonial and present-day colonial history, with specific focus on the complicity of public institutions in the genocide of Indigenous Peoples, while encouraging self-reflection and attention to ways in which clinical praxis reinforce colonial perspectives and authority over Indigenous Peoples. In the Canadian context, ongoing Indigenous cultural safety education is recognized as an important tool in ensuring health care providers are practising culturally safe care.[38–40] At Vancouver Coastal Health, this has culminated in the creation and implementation of an Indigenous-led cultural safety education program, which is currently being evaluated.

Participants also shared their perspectives of the importance of creating welcoming spaces for Indigenous Peoples and improved Indigenous representation in health care. This adds to previous research from Australia that has highlighted the importance of Indigenous-designed health care spaces,[41] though it is important to acknowledge that participants felt improving physical spaces would be futile in the absence of culturally safe health care. Additionally, increased Indigenous representation among health care providers is an important aspect of improving Indigenous Peoples' trust in the health care system, which is supported by existing evidence that increased diversity among health care staff is associated with improved health outcomes.[42]

While participants emphasized the importance of cultural safety education, welcoming health care spaces and more Indigenous representation in health care, they also highlighted the need for systemic changes that acknowledge the value and benefit of Indigenous perspectives on health and well-being. For some participants, this was realized through having received health care services in an urban Indigenous health clinic, which was designed by and for Indigenous communities and organizations seeking to establish culturally safe health care services. Through the incorporation of traditional healing into clinical practice and acknowledging the importance of culture and ceremony on health, this clinic provides insight into the operationalization of self-determination in health care and aligns with research showing the positive association between cultural and linguistic connection and well-being.[43–45]

Furthermore, the importance of Indigenous self-determination over health care services[46,47] and increased Indigenous leadership in health care decision-making and service delivery align with the calls to action presented by the Truth and Reconciliation Commission of Canada,[48] and there are several examples from BC that can provide guidance on how this can be accomplished. These include the establishment of the First Nations Health Authority,[49,50] whereby the provincial and federal governments ceded control over health care service delivery in on-reserve communities to the First Nations Health Authority, as well as the expansion of Indigenous leadership and teams within the regional health authorities, which includes the Vancouver Coastal Health Indigenous Health department. It is suspected that these efforts have led to an increase in life expectancy, a decrease in the youth suicide rate and a decrease in the diabetes prevalence rate among on-reserve Indigenous Peoples in BC.[51] However, the health gap between Indigenous Peoples and non-Indigenous populations has persisted[51,52] and the continued expansion of these efforts is needed.

Limitations

This study has several limitations. We did not consider the perspectives of health care providers, and research into their perspectives would be valuable. Additionally, most of the study sample consisted of Indigenous women, and future research into the experiences and perspectives of Indigenous men would be valuable. Nevertheless, this may be reflective of the historically matriarchal structures among many First Nations in BC, which is where most participants identified as being from. Results may not be generalizable to other urban settings, though findings from the government-commissioned report *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in BC Health Care*[14] suggest these experiences are common for Indigenous Peoples across BC, including in Victoria and Prince George. Additionally, we did not collect information on the Indigenous groups or Nations that participants were members of and were unable to discern differences in health care experiences or perspectives based on participants' Indigeneity. Lastly, participants were asked to share their historical experiences accessing health care services, and we were unable to determine whether these occurred recently or in the more distant past.

Conclusion

Although efforts are being made to reconcile the wrongdoing of the Canadian health care system and providers toward Indigenous Peoples, findings from this study highlight harmful discrimination, prejudice and racism experienced by Indigenous Peoples accessing health care services in Vancouver. This is problematic given that Indigenous Peoples are less likely to access health care and continue to experience worse health outcomes than non-Indigenous populations. Nevertheless, study participants point to promising practices, including the provision of cultural safety education to health care providers, creating culturally safe and welcoming spaces, and increasing Indigenous self-determination and leadership in health care.

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