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3 Identifying barriers to amputation preventive care in Canadian indigenous populations at high-risk for
4 lower extremity amputation
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36 **Tyrell Wees:** A medical student and researcher, he carried out data collection, transcribed data, reviewed
37 and edited data analysis, prepared first draft of the introduction and discussion.
38

39 **Mamata Pandey:** A research scientist at Saskatchewan Health Authority, she developed research plan,
40 developed focus group questionnaire in collaboration with community representatives, carried out focus
41 groups, analyzed data, prepared final manuscript draft, edited and incorporated feedback from all authors.
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3 **Susanne Nicolay:** As the clinical coordinator and registered nurse at Wellness Wheel, she worked in
4 collaboration with community Health managers, carried out focus groups, reviewed data analysis and
5 coordinated with community members to review data analysis, review and edit the final manuscript.
6

7 **Juandell Windigo:** As the Health Manager of Muskowekwan First Nation, Saskatchewan, she approved
8 the research plan, she helped develop the focus group questions, supported participant recruitment,
9 reviewed and edited data analysis report and reviewed, edited and approved the final manuscript draft.
10

11 **Agnes Bitternose:** As the Health Manager of George Gordon First Nation, Saskatchewan, she served as
12 the community representative, approved the research plan, helped develop the focus group questionnaire,
13 support participants recruitment, reviewed and provided feedback on the data analysis and reviewed and
14 approved the final draft of the manuscript.
15

16 **Dr. David Kopriva:** As the vascular surgeon and lead researcher, he develop the research project,
17 coordinated with community members to develop research plan, acquired funding, developed research
18 objectives and focus group questionnaire in collaboration with the other team members, reviewed data
19 analysis, and edited the draft manuscript.
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Table 1: Main themes, intermediate theme and quotes from focus group with community healthcare teams and patients.

Main theme	Intermediate codes	Quotes from participants
Factors impacting healthcare access	Healthcare available within communities	<i>“it comes down to talking with people who trust, trust is big with First Nations people. The way you talk to them will be the deciding factor if they're going to listen to you or if they're going to be non-compliant” [CHCT]</i>
	Supports from Community healthcare team	<i>“We do our best to refer them to a Podiatry and, connect them if it's serious enough with the Wellness Wheel doctors because they offer such great services to the community. We trust that they're going to send them to the right specialists to get the issues taken care of as quickly as possible” [CHCT]</i>
	Funding	<i>“While provincial health stopped funding Podiatry services we are covered through Non-Insured Health Benefits (NIHB) we didn't even realize it as a home care team. You can make this appointment. It's not going to cost you a thing and you're treaty number NIHB will cover it so we make sure to make them aware” [CHCT]</i>
	Lack of primary healthcare	<i>“lots of people don't have family doctors we see whoever we can see when we need to see a doctor..... there's times too where we can't get their doctors to sign off on medications but they need refills. But there are circumstances where the doctor will say I'll renew for one month, so we've arranged the refills for a month and then we got to make darn sure that the person comes in to see the doctor” [CHCT]</i>
	Travel Barriers	<i>“the travel rates has been like that for maybe 20 years., it hasn't changed. We give them \$57.60 to go to Regina for a specialized appointment” [CHCT]</i> <i>“And it's kind of hard to find someone to drive you to Regina for \$57 with the cost of gas,” [patient]</i>
	Lack of trust	<i>“big pharma are driven by greed. They probably have the cure to diabetes but They won't make as much money” [patient]</i> <i>“Most of us they don't trust people from here. They don't trust that they are professional enough to keep things confidential so that a barrier to accessing care” [CHCTs]</i>

	Racism and discrimination	<i>“as a nurse I had a sister who had an issue with her leg. The first thing I told her 1)Go to the hospital, go to emergency, 2) tell them you're not drug-seeking because your First Nation they're going to assume that right away, 3) ask for these tests, let's rule out a break because it's so swollen, let's see if there's a clot. Then the doctor spent less than five minutes with her, told her she had a skin infection, and sent her home She walked on that leg for another week, her leg was broken!” [CHCT]</i>
	Inadequate patient-provider communication	<i>“It seems to me that certain doctors want to just cut your leg off right away what's is it cheaper or does the doctor earn more for amputation. As opposed to trying to heal”[patient]</i> <i>“I don't know if he understood that they were taking his legs because he didn't speak English too well he's spoke his own language when he woke up, he's like, oh, what happened? so yeah that was a big loss for him”[patient]</i>
	Personal factors	<i>“I think the generational trauma has caused a lot of it so we look at the they're doing drugs alcohol model that is just a painkiller to them. There's extensive trauma from childhood that we've never dealt with, like the abuse. So I said before, so the trauma leads to a lot of illnesses too within your body.”[CHCT]</i> <i>“I've had diabetic ulcers and holes at the bottom of both my toes that went on for six years because I wouldn't leave work and sit there at let them heal well, now they're healed, but now I have a bone infection in my toe and I'm waiting for the doctor to phone me to tell me whether they're going to put me on IV to heal my bone or else if they're just going to cut off my big toe” [patient]</i> <i>“There's a stigmatism, I know that my client who has cancer and she is treating both traditional and western, she does not tell her doctor that she is treating with traditional medicine. She's scared to be blamed... that this is why it's not working or a lot of times the doctors don't understand the traditional ways right so right away there you get that stigmatism like you're doing something wrong ”[CHCT]</i> <i>“We have a dietician she gives us the foods but I have a problem a lot other people in the community have the same problem....it's really hard for the people to follow the diet because of financial issues .” [patient]</i>
Impacts on patient care	Healthcare delivery	<i>“A few years back client phoned me I went over there right away. She was having a stroke, I took her to the hospital. She had two mini strokes on the way to the hospital and they still made her sit I went up to the front and I tried I just told them where I was from and I was a CCA in community and how we've been sitting here just about an hour. She's now she had a massive stroke. Her face is red now. I explained to them right away when we first got in here that she's having a stroke her high</i>

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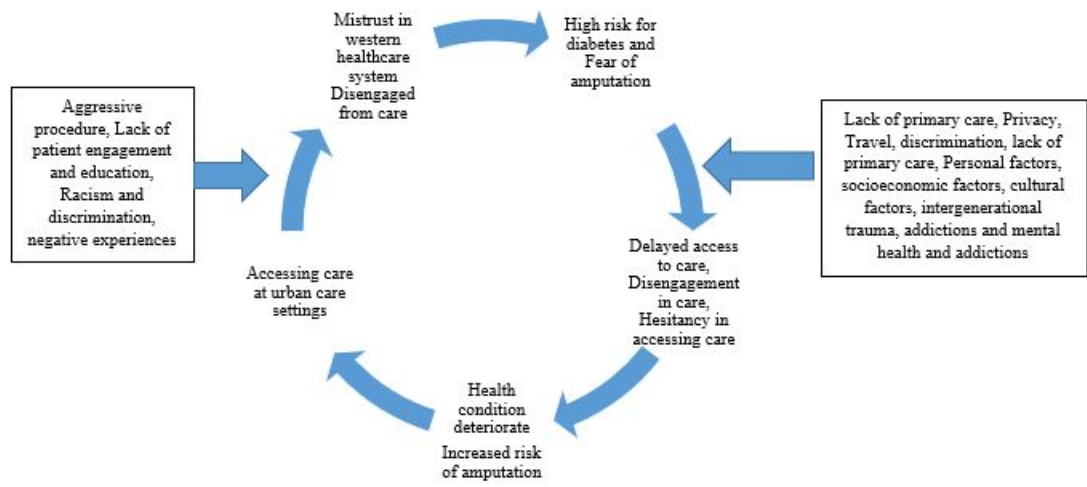
		<i>blood, her blood pressure, her sugars are way up I said he's going to have a heart attack, but they just let her sit there. Finally, when she did have a massive stroke there, that's when they raced around”[CHCT]</i>
	Healthcare coordination	<i>“A client from this community discharged from hospital has below the knee amputation. He had an instrument catheter. He wanted his meds and his leg site was still fresh, so his bandages were leaking....so that I could change on my own but As for everything else, I was kind of lost as to what to do with this man. I looked on his ehealth and even that was like barely helpful so it was really hard coordinating care for that for that fellow” [CHCT]</i>
	Delay in seeking care	<i>“People in the community are scared to lose their toe or the toes or their feet. A client just refused to go see the doctor and his big toe turned black only then he went to the hospital ended up losing that toe. Because he waited too long when the big toe started to heal, the other toes got infected, so he lost his foot. That person eventually lost his one limb below the knee and that all started, just from the big toe” [CHCT]</i>
	Delayed healthcare access	<i>“We had a single father last year discharged himself early with a VAC dressing because he had young kids all under the age of 12 and he was our primary provider ” ... “They come home early, a lot of them do discharge themselves and then they always end up going back all the time”[CHCTs]</i>
	After care	<i>“Client got fitted.... this bone here (indicating tibia) just rubs on that prosthesis and he's always got it open it hasn't been infected where it's bothering him... it's so frustrating because we went on September, for the eighth appointment.... they filed the prosthesis down. It's still worse, so it's been quite frustrating with his walking...I go home for lunch every day because of his health. His heart is also working only at 20% and like yesterday I went home and he fell and he couldn't get up, so he had to wait till I got home” [CHCT]</i>
	COVID-19 impacts	<i>“Pre COVID, we had our yearly health fair where every program that health and wellness offers where we set up booths and provided that information” [CHCT]</i>
Solutions	Stronger partnerships with urban care providers	<i>“Here it works good with the Wellness Wheel there's always some who advocate in there with the doctor But like somewhere else, there's not going to be someone out there advocating for you”[CHCT]</i>

	Improved education	<p><i>“Consistency is a major thing...also education on those pills 'cause I didn't know taking metformin was no good for my kidneys I took metformin for 12 years And then doctor said I need to get you off metformin Because metformin is filled with chalk actually blocks off your kidneys” [patient]</i></p> <p><i>“For people with first time diagnosis it would be good for like a doctor to explain to people after years of being diabetic about losing the veins and sensation in your leg and the circulation” [patient]</i></p>
	Innovative strategies	<p><i>“But I start eating less just small portions and that the nurses give me and eating less done more good than medicine, I didn't really change what I eat... I started eating less I went from 238 to 192 for my last A1c was 6.8 it went down as low as 5.8” [patient]</i></p>

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Figure 1. Interplay of social barriers causing positive feedback loop which perpetuates diabetic foot complications.



Abstract:

Indigenous people living on Canadian reserves are overrepresented in non-traumatic lower extremity amputation (LEA) populations. These patients are more likely to be younger, have diabetic foot infections, and have no previous revascularization procedures when compared with non-Indigenous LEA populations. These amputations are associated with significant physical, emotional, and psychological comorbidities as well as contribute to a major cost to the healthcare system. Employing a community participatory research design two community representatives were engaged. Community representatives informed research design, assisted with data analysis and approved final manuscript. The aims of this project were to identify specific barriers preventing Indigenous patients in high-risk communities from accessing preventative care directed at limb salvage, as well as explore patient's experiences with healthcare systems and identify potential solutions. Using purposeful sampling five semi-structured focus groups were conducted with community healthcare teams and patients who were at risk for, or had previously undergone, a non-traumatic LEA. Employing thematic analysis, three major themes were identified: factors impacting healthcare access, impacts on patient care, and possible solutions. Analysis of the patient's and community healthcare providers' perspectives indicated that a complex interplay of social, economic, and systemic issues feeding into a positive feedback loop perpetuating LEAs in Indigenous patients living on reserves (Figure 1). Findings of this project are consistent with Anderson and Newman's framework of healthcare utilization and access. Regional and systemic changes are needed to eliminate these barriers and create equitable access to healthcare for Indigenous patients at risk for lower extremity amputations.

Key words: Lower limb amputation, Indigenous communities, systemic barriers

Introduction:

Within Canada, lower extremity amputations (LEAs) were performed over 44,000 times between 2006 and 2011.¹ In the United States of America, over 150,000 non-traumatic amputations were performed in 2015 alone.² In Saskatchewan, LEAs are performed on average 419 times per year.³ LEAs put significant physical, emotional, and psychological stress on many patients undergoing the procedure. Nontraumatic amputations most frequently occur due to the presence of peripheral arterial disease (PAD) and diabetes mellitus (DM) and occur more frequently in the lower extremities than in the upper extremities.

Indigenous patients represent 23% of all patients undergoing LEA in Southern Saskatchewan while only representing 10% of the total population of Saskatchewan.⁴ Indigenous populations undergoing amputation were more likely to be younger, have diabetic foot infections, have no prior revascularization procedures, and live in First Nations communities.⁴ Comparatively, non-indigenous populations undergoing LEA in the same time period were more likely to be older, have chronic limb threatening ischemia (CLTI), and have previous revascularization procedures.⁴

Amputations confer a tremendous burden to patients, patients' family, and the healthcare system. Patients who underwent LEAs often describe tremendous difficulties with mobility, self-image, and societal stigma, which impacts their personal and professional lives.⁵ Patients with LEAs often require longer in-hospital stays, re-admissions for complications, and exacerbation of their co-morbid conditions.^{6,7,8} While the estimated cost for LEAs in Canada are not available, the annual cost of LEAs in the United States of America are in excess of \$4 billion.¹ With adequate patient education, chronic disease management, intensive vascular care, and access to multidisciplinary teams, wound clinics have been observed to prevent up to 50% of amputations.⁹

A high incidence of LEAs among Southern Saskatchewan's Indigenous population observed in a retrospective chart review⁴ motivated this study. The study objectives were to: 1) identify healthcare access barriers for high-risk Indigenous patients in Southern Saskatchewan; 2) explore experiences of patients who underwent amputations for diabetic foot ulcers (DFUs) and those who sought DFUs care; 3) identify potential solutions to reduce healthcare barriers.

Methods:

Employing a community participatory research design^{10,11}, in partnership with representatives from two interested communities, a collective decision was made to explore the perspective of both Indigenous healthcare providers and patients. Community representatives edited the focus group questions. Using purposeful sampling strategy community representatives recruited local healthcare teams and individuals living with diabetes or who have experienced DFUs and/or amputations. All participants were informed

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3 about the study objectives and research team. They received the questionnaire and signed informed
4 consent. Honoring the Indigenous oral traditions¹² the first three authors used open-ended questions
5 exploring participants' experience with DFUs, amputations, and healthcare access barriers. Four focus
6 groups were carried out with community healthcare teams (CHCTs) from two communities (n=18). One
7 focus group was conducted with patients (n=10). All participants provided informed consent. Focus
8 groups were 90-135 minutes long and were audio-recorded. Saskatchewan Health Authority Research
9 Ethics Board (REB-20-126) approved the study.
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15 **Analysis:** All audio-recorded focus group data were transcribed verbatim and analyzed employing
16 software Package QSR NVivo® 9¹³. Following the qualitative methods described by Miles, and
17 colleagues¹¹, the transcribed data were read line-by-line by the second author and 183 base-level codes
18 were identified. The interview guide was consulted ensuring all discussion points and any new emerging
19 ideas were coded. An appropriate descriptive title was assigned to each of them. Similar base codes were
20 grouped under 23 intermediate codes¹⁴. Diagrams were used to group the 23 intermediate codes under
21 three main themes. The data analysis was extensively reviewed by other researchers on the team and
22 community representatives ensuring personal and professional biases were addresses and the data analysis
23 truly reflects the voice of the community members. Since data saturation was reached a collective
24 decision was made to stop further collection. All feedback was incorporated¹⁵ and Figure 1 was finalized.
25 The final manuscript was approved by community representatives and they serve as co-authors.
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33 **Results**

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35 **Factors impacting healthcare access:** A combination of systemic, socio-cultural, economic and personal
36 factors impacts patient's ability to access healthcare services available within the community, nearby
37 communities, and in urban centers Refer to Table 1.
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41 **Healthcare available within communities:** Homecare, nursing, immunizations, medication delivery,
42 diabetes education, nutritional support, and nutritional education are provided. Health promotion
43 programs are provided to build trusting relationship with patients, as trusting relationships enhance
44 healthcare access, utilization and adherence.
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48 **Community healthcare team supports:** CHCTs support clients to access healthcare services within
49 community, at urban centers, post discharge, and during health emergencies.
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52 **Funding:** Additional coverage for orthopedic shoes for patients with DM, vary annually and has been
53 limited during the COVID-19 pandemic. Patients might not be aware of the Podiatry services covered
54 through Non-Insured Health Benefits (NIHB) and might not access those.
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3 **Lack of primary healthcare:** CHCTs coordinate care with visiting Wellness Wheel Clinics doctors for
4 primary care needs. However, the lack of consistent primary healthcare in communities causes patients to
5 seek care at various walk-in clinics which leads to lack of continuous care and monitoring of chronic
6 diseases.
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10 **Travel barriers:** Limited space on medical vans, that transport patients for specialist care in urban centres,
11 leads to prioritization of medical conditions and patients might not be able to utilize these services.
12 Privacy issues also discourage patients from utilizing these services. Reimbursement for those arranging
13 their own medical transportation is often insufficient to cover the true expenses.
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17 **Lack of trust:** Both patients and healthcare providers emphasized the importance of a trusting relationship
18 for patients' continued engagement in healthcare. Lack of consistent primary healthcare providers caused
19 a lack in trust in physician care. Perceived lack of privacy further inhibited patients from seeking care in
20 communities when needed.
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24 **Racism and discrimination:** Patients and healthcare providers described several incidents of racism and
25 discrimination experienced in healthcare settings outside of the community. They reported experiencing
26 longer wait times in both walk-in and emergency departments, being labelled as drug-seeking, and treated
27 with disrespect or having symptoms ignored due to their ethnicity. Previous negative experiences in
28 western healthcare settings further exacerbate mistrust in the western healthcare.
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32 **Poor patient-provider communication:** Patients and CHCTs observed that healthcare providers in
33 western healthcare settings often missed opportunities to educate or engage patients in their chronic
34 disease management leading to further confusion for the patient. Lack of communication between
35 physicians and patients led to patients questioning the treatment provided by physicians.
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39 **Personal factors:** Age, gender, family responsibilities, and lack of child-care may prevent them from
40 adequately caring for their own health. Insufficient patient education and understanding of chronic disease
41 management has led some patients to avoid care until a problem becomes severe.
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45 Both CHCTs and patients indicated that the impacts of intergenerational trauma have caused downstream
46 effects such as mental health issues, addictions, or even denial about their medical conditions. These co-
47 pathologies cause patients to delay seeking care or disengage from their healthcare which leads to
48 exacerbation of their condition and symptoms.
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51 Individual spiritual or religious beliefs may impact healthcare access as some patients may prefer
52 traditional medicines instead of seeking western medical care. Financial barriers such as: healthcare
53 equipment costs, medication costs, travel expenses, cost and access of healthy food alternatives can
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3 impact access and utilization of medical care. Patients mentioned financial strains influencing their ability
4 to take time off work to care for their health.
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7 **Impacts on healthcare utilization:** Factors impacting several aspects of the quality of care received,
8 healthcare access, utilization, extent to which treatment strategies were acceptable to patients, and health
9 outcomes are illustrated in Table 1.
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12 **Healthcare delivery:** Healthcare providers and patients described suboptimal experiences by themselves,
13 their family, friends, and others in the community where they experienced delayed care, important
14 symptoms were missed, insufficient investigations ordered, and treatments were delayed, which lead to
15 exacerbation of their condition.
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19 **Healthcare coordination:** Coordinating healthcare services and policies among various jurisdictions can
20 result in healthcare navigation challenges. CHCTs acknowledged they often have insufficient information
21 to care for patients post discharge from urban settings, thus leading to inadequate support for the patients.
22 CHCTs often engage in creative problem solving to adequately support their patients, leading to increased
23 workload, delayed continuity of care, and delayed access to medications and medical supplies.
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27 **Delay in seeking care:** Some patients hesitate to access available healthcare in communities due to
28 confidentiality issues. Furthermore, patients described avoiding care until a problem had become too
29 severe to ignore. Lack of knowledge about their health conditions, preventative medicine, fear of
30 amputation, and negative healthcare experiences by friends and family cause patients to delay accessing
31 healthcare services. Additionally, the lack of trust in western healthcare also prevents patients from
32 accessing care both in communities and in urban centers.
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36 **Delayed healthcare access:** Patients dependent on family members for transport and support during
37 medical appointments might have to delay healthcare access. Furthermore, CHCTs described patients
38 often do not want to feel like a burden to their families or healthcare workers and thus avoid seeking care
39 until absolutely necessary. Familial responsibilities might lead patients to put those responsibilities above
40 their own health, which may lead to untimely self-discharge from hospitals. Lack of knowledge about
41 patients discharge plan often results in CHCTs lacking the necessary supplies or medications to
42 adequately support these patients in community. This increases the risk of subsequent infections,
43 readmissions, and further complications for patients.
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47 **Aftercare:** Amputation puts significant strain on the physical, mental, and spiritual aspects of patients'
48 lives. Individuals must manage recovery with limited physical and mental support. Patients described
49 slow, complex recovery which was exacerbated by comorbid conditions these patients had. Additionally,
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3 patients and families must coordinate various appointments with surgeons, specialists, rehabilitation, and
4 prosthetic clinics which put further stress on financial situations for families.

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7 **COVID-19 impacts:** The COVID-19 pandemic put additional stress on communities and patients as
8 funding was reduced for footwear and the opportunities to engage the community through health fairs and
9 education sessions were limited. Fear of infection deterred patients from travelling in medical vans
10 leading to delayed access to care, support, and education.
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14 **Solutions:** Patients and CHCTs identified several strategies such as building stronger partnerships with
15 urban and rural healthcare providers, improved education for both patients and healthcare providers, as
16 well as innovative strategies to improve patient's overall health. Refer to Table 1.
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19 **Stronger partnerships with urban care providers:** CHCTs indicated that a stronger partnership between
20 urban healthcare providers and continued advocacy will enhance access to healthcare services.
21 Additionally, CHCTs noted that Wellness Wheel Clinic providers were eliminating barriers to care,
22 enhancing continuity in care received and overall quality of care leading to better healthcare outcomes.
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25 **Improved education:** Patients mentioned that education about chronic disease management, medication
26 dosage, and information about their side effects was necessary for them and especially those who are
27 newly diagnosed to adhere to treatment plans. Education should be provided in a language that is easy to
28 follow.
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33 Health promotion, diabetes education, and prevention should be started early on with children at
34 elementary schools. CHCTs would benefit from a list of services in urban centers to adequately refer
35 patients for healthcare services. Healthcare providers should receive cultural competency training and
36 received information about intergenerational trauma that continues to impact the health outcomes and
37 address systemic racism and discrimination.
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42 **Innovative strategies:** Healthcare providers mentioned that alternative strategies such as increased
43 nutritional support and dietary consultation which has showed promising results are needed to engage
44 patients in their healthcare. Other strategies such as health education days which included teachings in
45 self-care, personal grooming, foot care, and diabetes prevention are needed. These education days have
46 seen good turn outs and may be more accepted by community members. Furthermore, access to exercise
47 options was also mentioned as an adjunctive measure to help improve overall health of community
48 members.
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53 Discussion

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3 The study results are consistent with Anderson and Newman's framework of healthcare
4 utilization and access.¹⁰ The study results demonstrate complex interactions between systemic, personal,
5 socioeconomic, and sociocultural factors that impact access to healthcare services, utilization of
6 healthcare, quality of care received, and health outcomes. Due to jurisdictional policies and lack of
7 sufficient funding, coordination of care on and off-reserve can be challenging to organize for CHCTs and
8 patients. The lack of primary healthcare services in communities means residents are often required to
9 travel to urban centers to receive the necessary care. However, there are significant travel barriers that
10 patients and CHCTs must navigate. While medical taxis are available within communities, space is
11 limited, trips require full day commitments, and patients are often concerned with privacy and safety
12 especially during the COVID-19 pandemic. Patients arranging their own transportation are often faced
13 with insufficient reimbursement based on rates to the nearest city, not to access the necessary care or
14 specialist.
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23 At urban centers, patients are often subjected to discrimination and racism. Patients and CHCTs
24 described several instances where indigenous patients experienced longer wait times, misdiagnoses,
25 insufficient investigational studies, lack of adequate treatment, and being labelled as "drug-seeking"
26 despite presenting significant symptomatic evidences. Additionally, urban healthcare providers frequently
27 provided insufficient education to patients regarding their disease, management strategies, and potential
28 complications. These negative experiences create hesitancy to seek care among patients, which often
29 leads to disengaged care, early self-discharge from care, and delaying access to care for future conditions.
30 This causes further deterioration in their health condition, re-infection, readmission, and more aggressive
31 procedures to manage their complications. Aggressive procedures such as amputation have led patients to
32 question physicians' motives deepening distrust within the western healthcare system. This has caused
33 patients to delay seeking care for future medical conditions, thus creating a vicious cycle of
34 complications, negative experiences, aggressive procedures, and distrust as exemplified in Figure 1.
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42 While patients have access to dieticians within the community, availability and access to healthy
43 foods are insufficient for most patients. Furthermore, intergenerational trauma from residential schools
44 and the sixties scoop have led to mental health disorders, addictions, and further distrust. These are often
45 overwhelming barriers that prevent patients from being able to adequately care for their own medical
46 conditions..
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51 Patients and CHCTs recommend increased education, increased supports for diabetic patients,
52 and stronger partnerships with urban care providers to adequately address barriers to healthcare access,
53 quality of care delivered, and healthcare outcomes for Indigenous patients with diabetes and foot
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Limitation:

This study includes perspectives of two First Nation community members in central Saskatchewan, and may have limited generalizability. Conducted by healthcare researchers representing publicly funded healthcare system, the interpretations could be biased. Individuals with prior negative experiences with the publicly funded healthcare system may have chosen not to participate in this study, resulting in selection bias.

Recommendation:

1. Increased education for urban healthcare providers on access barriers for indigenous patients, systemic racism experienced in healthcare setting and intergenerational trauma that impact health outcomes for Indigenous peoples.
2. Increased funding for medical travel, health promotion program and reliable on-reserve primary healthcare.

Conclusion

The study results identify multiple social factors associated with increased risk of LEAs in our study locations. These social factors are compounded by positive feedback loops perpetuating illness severity and thus requiring more invasive interventions. Adequate redress of these items will be required to improve outcomes for individuals residing in First Nation communities and are at risk of LEAs.

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