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Barriers and supports for Indigenous youth and young adults with childhood- onset chronic health conditions transitioning from pediatric to adult healthcare: a qualitative study

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Abstract

Background This study examined the experiences of Indigenous youth and young adults with pediatric onset chronic health conditions who had or were about to transition from pediatric to adult healthcare services. Transition is the process by which youth develop the knowledge and self-management skills needed to manage their health condition, ideally beginning around age 12–13 and continuing until the mid-20s. There is a growing body of literature on healthcare transition, but there is an absence of literature on Indigenous youth, who face additional barriers to accessing healthcare relative to non-Indigenous Canadians. The primary objective of this study was to identify the supports and barriers for Indigenous youth with childhood-onset chronic health conditions transitioning from pediatric to adult healthcare services.

Methods The research was done in the province of Alberta, Canada, in collaboration with a Community Advisory Committee comprised of Indigenous healthcare providers, Elders and Knowledge Keepers and guided by a community-based participatory research approach. Semi-structured qualitative interviews ($n = 46$) were conducted with Indigenous youth, caregivers, and healthcare providers. There were three Talking Circles, two for youth (9 participants) and one for caregivers (6 participants). Three research assistants coded the transcripts thematically using NVivo. The key findings were presented to the Community Advisory Committee for feedback to validate the interpretation of the qualitative data.

Results The thematic findings include: (1) systemic inequalities exacerbate gaps in healthcare; (2) intergenerational trauma created unique barriers for Indigenous youth; (3) long-term relationships with care providers as a protective factor; (4) the incorporation of Indigenous worldviews into healthcare services to aid transition; and (5) assuming new responsibilities as an adult. The participants provided recommendations to improve healthcare service delivery including the need for Indigenous transition supports in community and improving education for healthcare practitioners about transition and Indigenous worldviews.

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Conclusion This study demonstrates the complexity of the transition experience for Indigenous youth with pediatric onset chronic health conditions. The identified barriers to successful transition could be addressed through systems level changes and the development of Indigenous specific transition support services. Such approaches need to be Indigenous-led and incorporate Indigenous culture, language, and teachings.

Keywords Adolescent health services, Health services, Indigenous, Transition to adult care, Qualitative research

Background

Advances in medical and surgical care over the past three decades have substantially increased the survival of many childhood-onset chronic health conditions, resulting in a growing population of adolescents requiring lifelong specialty healthcare [1]. Transition is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems [2].” Transition is a lengthy process rather than a single event, and ideally begins at approximately age 12 or 13 and continues until the mid-20s [3, 4]. Transition includes, but is not limited to, the transfer from pediatric to adult care [5]. Youth and young adults generally leave pediatric care at 17 years of age in Canada, as most children’s hospitals mandate that adults who have reached their 18th birthday cannot be admitted as inpatients, with rare exceptions. Transfer is a single point in time when the responsibility of care for the young adult patient moves from a pediatric to an adult healthcare provider.

Youth and young adults with special healthcare needs are at high risk of experiencing gaps in care when transitioning from pediatric to adult healthcare systems, which can result in youth falling completely out of care [6], experiencing disease-related complications [7, 8], and needing avoidable emergency department visits [9] and hospitalizations [10]. Barriers to successful transition include lack of preparation of youth by providers, and socio-demographic factors such as unstable housing [11, 12], low parent educational attainment and poverty [13].

Indigenous peoples in Canada (First Nations, Inuit and Métis) experience a higher burden of chronic health conditions relative to the general population [14, 15]. Colonization, the process of settling among and establishing control over Indigenous people, is the single-most profound determinant of Indigenous Peoples’ health and well-being [16]. Forced assimilation practices in Canada were underscored by ideologic racism and resulted in residential schools, Indian hospitals, laws and policies such as the Indian Act, and large-scale removal of Indigenous children from their homes, which have driven inequalities in the social determinants of health and had profound, long-lasting and ongoing negative impacts on emotional, spiritual, mental, and physical health for Indigenous Peoples [15, 17–20].

People aged 15–24 make up 17% of the Indigenous population in Canada, 44% of whom report having at least one chronic health condition that was diagnosed by a health professional [21]. To date, little is known about the transition experiences of Indigenous youth and young adults. This is an important knowledge gap, as many Indigenous persons in Canada face additional barriers to accessing health care. Structural inequalities are present for Indigenous youth [22]. Reasons for this are variable but include residing a significant distance from tertiary pediatric care, lasting effects of colonization including racism within mainstream health care, suspicion, distrust and fear of health care providers and systems, and socio-economic deprivation [16, 23, 24].

In full collaboration with members the Nêhiyawak (Cree) community of Maskwacîs located in central Alberta, Canada we sought to identify barriers and facilitators of pediatric to adult transition from the perspectives of young adults, their parents or caregivers, and health care professionals experienced at working with Indigenous youth, with the intent of developing a community-derived intervention building on the research findings.

Methods

This research was conceptualized in 2020 by author AM who approached author RL from the University of Alberta. In partnership, they created a research team that was comprised of University of Alberta researchers and a Community Advisory Committee (CAC) that included Elders, Knowledge Keepers, and healthcare providers from Maskwacîs. A formal partnership was agreed upon by the CAC, Maskwacîs Health Services, and the University of Alberta researchers. CAC meetings were held 4–5 times per year for the duration of the project. All project decisions were made by group consensus. The research team hired a community-based researcher from Maskwacîs to support data collection.

This project was guided by an overarching framework rooted in community based participatory research

(CBPR) approaches that uses an experiential, participative-knowing epistemology [25]. Fundamental to this approach is the knowledge that community members are the experts in their own context and possess knowledge that is crucial for research that will benefit their own community [26]. Relationships were a foundational underpinning to the team's collective aims and were based on trust, mutual understanding, respect, compassion, humility, and a spiritual and relational responsibility to one another. Moreover, the team deliberately utilized a strengths-based approach that avoided focusing research on community deficits, problems, or pathologizing community members, but leveraged community resilience, opportunity, and capacity and centers on Nêhiyawak knowledge and culture [27, 28].

Study inclusion criteria were (a) Youth and young adults who identified as Indigenous, lived in Canada, were between the ages of 16–30 and had a pediatric-onset chronic health condition; (b) Caregiver participants were parents, guardians, and caregivers of the youth population described; (c) Healthcare providers were those who worked with Indigenous youth aged 16–30 years of age with chronic health conditions in their clinical practice. Caregiver/youth dyads were invited to participate in the study; however, it was not necessary for a caregiver to be accompanied by their child and vice versa.

Having access to a family doctor or an adult specialist doctor was not a requirement of participation, as some individuals are unable to access a family doctor or specialist, even when they need one. Family doctors in Canada are primary care providers who can diagnose and treat a variety of health conditions and diseases for all ages. Adolescents and young adults do not need to physically transfer out of the practice of a family doctor when they reach their 18th birthday, and therefore family doctors, when available, can help provide continuity of care for transition-age youth and young adults.

Data generation

Data generation approaches included semi-structured interviews and Talking Circles, which are similar to focus groups but are rooted in Indigenous cultural practices, including ceremony and sacred meaning [29]. Interviews and Talking Circles aligned with the worldviews of Indigenous CAC members which rely on storytelling traditions and allow for the gathering of information through ongoing community engagement and relationship building [29, 30]. A community-based research assistant was hired and trained to conduct the interviews, which were done in person or by telephone and took approximately 45 min. The interviewer asked participants about supports and barriers to transition from pediatric to adult healthcare. Interview guides were tailored to each of the three participant groups (see: Supplementary materials). Interview and Talking Circle guides were developed for this study with input from the CAC members and not previously published elsewhere (see: Supplementary materials).

Participant recruitment

Recruitment and data collection took place from 2021 to 2023. Recruitment of youth and caregiver participants relied on a range of strategies. In person recruitment was done at participating outpatient medical clinics and at health and youth focused events within local communities. Flyers, social media, community newsletters and advertisements on the local radio were used. Indigenous participants in the control arm of the Transition Navigator Trial [31], a large transition related clinical trial recently completed within Alberta were also invited to participate in the current study. Healthcare provider participants were recruited using the above methods, as well as snowballing techniques of existing clinical colleague relationships to the research team.

All youth/young adults and caregivers were invited to participate in semi-structured interviews and an optional Talking Circle. The Talking Circles were optional throughout the study, as we recognized that not all participants would be comfortable participating in a group event. Healthcare providers were enrolled for semi-structured interviews only.

Three Talking Circles were held, two for youth participants ($n=9$) and one for caregivers ($n=6$). The Talking Circles were hybrid, allowing participation in person or by telephone, and took approximately two hours. The Talking Circles were moderated by a research assistant from the Maskwacîs community. Elders from the CAC were present to provide opening prayer and smudging as well as guide the circle. Audio recordings of interviews and Talking Circles were transcribed verbatim.

Youth, young adult and caregiver participants received a $50 gift card for participation in an interview and an additional $50 for participating in a Talking Circle as well as protocol. Healthcare provider participants received a $25 gift card for participation in an interview.

Ethics

Community approval for this research was obtained from key Elders, Knowledge Keepers, and community members that were part of the CAC, as well as from the Chief Executive Officer of Maskwacîs Health Services. Recruitment methods, interview and Talking Circle guides were co-developed, reviewed and revised by the CAC. The study was approved by the University of Alberta Health Research Ethics Board (Pro00095750), which adheres to the Tri-Council Policy Statement 2, Chap. 9:

Research Involving the First Nations, Inuit and Métis Peoples of Canada [32]. Prior to the generation of data, a research agreement was collaboratively drafted by the CAC and signed by the Elders on the CAC as well as the Chief Executive Officer of Maskwacîs Health Services. All study data is co-owned between the community and researchers, with storage at the University of Alberta and at Maskwacîs Health Services. The CAC was involved and made decisions at all stages of the project, providing ethical counsel, and ensuring research moved forward in culturally and community appropriate ways. All interview and Talking Circle participants provided written or verbal informed consent. Consent and demographic data were collected and managed using REDCap [33, 34] electronic data capture tools hosted and supported by the Women and Children's Health Research Institute at the University of Alberta.

Data analysis

The transcripts were coded using thematic analysis [35]. Author KD conducted a preliminary analysis of the transcripts to identify an initial set of codes. The CAC provided feedback on the early coding. Two team members (AC, MG) independently read the same four interview transcripts to identify themes using the codes identified by KD. The remaining transcripts were split evenly between the coders who coded all the transcripts thematically and met regularly to ensure reliability of coding. The final themes and recommendations for future action were reviewed by the research team and CAC to validate the thematic interpretation of the data.

Positionality

The research team was comprised of community Elders and Knowledge Keepers, Indigenous persons from Maskwacîs having lived experience with childhood-onset health conditions, on and off Nation healthcare providers, and academic research partners. Positionality statements for all research team and CAC members are provided in the Authors' Information section.

Rigor

The research team used an interview guide for the semi-structured interviews and Talking Circles to ensure consistency among the participants. Recruitment stopped once data saturation was reached. Rigor was also achieved through ongoing and comprehensive review on the interpretation of the findings and analysis in collaboration with the CAC. The two authors who coded the transcripts met regularly to discuss thematic areas and ensure consistency, in addition to sharing the findings with the CAC.

Results

All but one of the interview participants resided in Alberta. Semi-structured interviews were conducted with 22 youth, 13 parents/caregivers, and 11 healthcare professionals. Of the youth participants (68% female, mean age 24 ± 5 years), 77% had already left pediatric care, 82% reported having a family doctor and 73% were receiving care from a healthcare specialist. The youth reported a range of chronic conditions, and many reported having more than one diagnosis. Overall, the most reported category was mental health conditions, which was disclosed by 14 of the 22 youth participants. Of the 17 youth/young adult participants who had already transferred to adult care, 13 (76%) received care from a family doctor, 12 (71%) receive care from a specialist, and 3 (18%) had no usual source of care, meaning they did not receive care from a family doctor or a specialist. Among those still in pediatric care, 1/5 (20%) was age 18 or older (24 years). The youth participant demographics are reported in Table 1. Caregiver demographics are reported in Table 2.

Eleven of the participants were healthcare providers with experience providing care to Indigenous youth, although they did not necessarily provide care to the youth participants within this study. Seven of the healthcare providers worked in First Nations communities in Alberta and four worked in urban settings. The healthcare providers worked in a range of roles including Registered Nurses, family physicians, allied healthcare providers, specialist physicians, a program coordinator, and a social worker. The healthcare providers worked in a range of settings including tertiary care centres, children's hospitals, First Nations health services, specialty adult care, and a pediatric clinic. Three were primarily or exclusively pediatric providers, 3 were primarily or exclusively adult providers and 5 worked with both adult and pediatric populations within their practice.

Theme 1: structural inequities exacerbate Healthcare gaps

Many of the Indigenous youth participants reported that their access to healthcare services were generally impacted by social and economic resource disparities due to colonization. One recurring example from the interviews and Talking Circles was a lack of primary healthcare services in their community, which was not just a barrier to successful transition but for accessing healthcare services throughout the life course. Many of the participants spoke about the challenges of living in First Nations or rural communities which required travel to cities for care, as a caregiver participant noted:

> *It is challenging when you're on the reserve. There's no services. You have to come to the city for services.*

Table 1 Youth/Young adults participant demographic data

Category	Interview Participants *N* = 22 (%)	Talking Circle Participants *N* = 9 (%)
Gender		
Female	15 (68)	5 (56)
Male	5 (23)	2 (22)
Two-spirit	2 (9)	2 (22)
Age in years (mean, SD)	24, 5	26, 2
Location of Residence		
Edmonton	8 (36)	4 (44)
Maskwacîs	4 (18)	1 (11)
Other area in Alberta	9 (41)	3 (33)
Out of province	1 (5)	1 (11)
Currently…		
employed	10 (45)	6 (67)
attending high school	4 (18)	1 (11)
attending college or university	6 (27)	2 (22)
has a family doctor	18 (82)	7 (78)
has a pediatrician	3 (14)	1 (11)
receiving specialty care	16 (73)	7 (78)
transitioned to adult care	17 (77)	8 (89)
Category of health condition(s)*		
Neurological	1	1
Cardiovascular	2	1
Respiratory	1	0
Renal/Urinary	1	0
Hematological	1	1
Autoimmune	1	0
Oncology	1	1
Endocrine	2	2
Mental health	14	4
Sensory	1	1
Developmental	1	0
Trauma	3	2
Other	3	3

*% not noted for category of health condition as many youth had more than 1

Table 2 Caregiver participant demographics

Category	Interview Participants *N* = 13 (%)	Talking Circle Participants *N* = 6 (%)
Gender		
Female	12 (92)	4 (67)
Male	1 (8)	2 (33)
Role		
Parent	10 (77)	5 (83)
Caregiver	2 (15)	1 (17)
Legal guardian	1 (8)	0
Location		
Edmonton	4 (31)	1 (17)
Maskwacîs	4 (31)	4 (67)
Other area in Alberta	5 (38)	1 (17)
Currently, child…		
has a family doctor	10 (77)	4 (67)
has a pediatrician	1 (8)	2 (33)
receiving specialty care	10 (77)	6 (100
Child has transitioned to adult care	9 (69)	3 (50)
Category of youth child's health condition*		
Neurological	2	1
Genetic/Metabolic	1	0
Cardiovascular	2	2
Renal/Urinary	1	0
Mental health	6	1
Sensory	2	1
Developmental	1	0
Cancer	1	1
Other	1	0

*% not noted for category of health condition as many youth had more than 1

> *Like we got to go to Calgary to see our [specialist] now. There's no support groups in Indian country. (Caregiver Talking Circle Participant)*

As a result, transportation was frequently cited as a barrier among all the research participants. Many participants reported that their community offered transportation for healthcare appointments. However, all the participants who had used this service found it undesirable because it would require them waiting for all the others from the community who also had appointments in the city, often traveling without money for food, and having to wait outside, sometimes in Canadian winter conditions. Arranging transportation was often a barrier for youth, especially those who had other responsibilities such as caregiving for their own children, attending school, or work. There were also difficulties for some participants to get their medication or for routine bloodwork because their communities did not have a pharmacy or lab nearby. Some youth reported feeling that their healthcare providers did not understand the difficulty of maintaining their healthcare plans, because the providers had not worked on or visited a First Nation community and were consequently unaware of the realities of life on reserve. The challenges of accessing healthcare, for some, meant that several of the participants eventually had to make the difficult decision to move to or closer to urban centers to ensure their prompt access to specialists and emergency departments.

Many of the participants spoke about the healthcare system as one that was not designed with consideration for Indigenous people, especially those living on reserve. Participants felt that healthcare service delivery were intended for white, middle-class patients, which placed Indigenous people at a disadvantage. Moreover, there remains ongoing distrust among many Indigenous people of the healthcare system that can be another barrier to accessing care. One healthcare worker expanded:

> *…[O]ur healthcare system is based on the white middle-class model, and the expectations, the standards, the way that we work, is based on the white middle-class […] And that expectations, and the standards, and the boundaries that we have in that system, do not fit with people here on the reserve. They're not white. They don't live in the white world. […] and we try to apply our white answers to the Indigenous problem, and it doesn't work. It never works. Because, you know, we throw money at it, whatever, but it doesn't work most of the time […] there's a lot of mistrust between the Indigenous people and the white world, and the idea that to get healthcare you have to be white. (HCP12)*

Overall, all the participants spoke about healthcare inequities that are specific to Indigenous communities due to colonization and the chronic underfunding of on-reserve healthcare services, which was a significant barrier for successful transition.

Theme 2: intergenerational trauma

Research participants noted that intergenerational trauma due to colonization was a barrier for both youth and their caregivers. One participant noted her avoidance of dental care due to the stories her Kohkum (grandmother in Cree) shared with her about her experience of getting dental work while attending a residential school:

> *I absolutely refuse to go [to the dentist] and like if I get calls, I like will blow it off or something. Or if I need something major, I literally need to be sedated to go to the dentist. Because I remember a story my Kohkum told me of when she was a little girl, they would do dental work on the residential school students including her without any anesthetic. And that traumatized me as a child, and I carry that with me forever. (Youth Talking Circle Participant)*

Some of the youth did not get the healthcare services that they needed because their caregivers struggled with substance use, which for some, meant that the youth also had developmental delays or fetal alcohol spectrum disorder. Some of the youth also used substances to cope, which made it difficult to maintain healthcare appointments and for some, was detrimental to their well-being. Others found strength and healing by leaning into their culture to overcome addictions.

> *Many of our kids have fetal alcohol syndrome or some developmental delay because of the addiction in the family in and around them, and that be their parents, their siblings. And when you live in a family where addiction is a problem, sometimes you can go a whole day or a day and a half without food. You might be abused in some way. There are a lot of family issues here that you would not see in the White world. (HCP12)*
>
> *Um, so I used substances to cope, for the longest time. I used drugs and alcohol. Like I was a meth addict for four years. I drank since I was 16, so I've been sober for about two years now, and for my mental health-wise, it was the best decision I've made, because I had to – I had to deal with the real, and I had to feel the real in order to deal. And because I did that, and because my relationship with the culture, it's my issue isn't a major anymore. (Y171)*

Participants stressed that it was critical for healthcare providers to be knowledgeable about colonization and intergenerational trauma to inform their service delivery, as one caregiver described:

> *I think that especially being First Nation, and the older I get, the more I see that, you know, like there's just so much of the intergenerational trauma tied into all of the other stuff as well. So having that understanding and being able to come at it with those pieces as well, you know? Because yeah, if you're not willing to look at the whole picture, then you're not – like it's like you're blind, you know, to what's actually happening. And just because somebody is a doctor doesn't mean that they don't have all those limitations. So yeah, I think really, just like education about like, you know, Canada, and our history, and the First Nations, and how those things play a part in who our children are, you know, and what kinds of things that they're dealing with, what kinds of barriers they're experiencing or facing… (CG18).*

The youth explained the importance of trauma-informed care for Indigenous people to aid in transition:

> *Being trauma-informed makes the [transition] process a lot more easier, because as Indigenous people exist in a perpetual state of like grief and trauma. […] like we should still be afforded like basic human decency and everything. And that's a huge thing too, is that a lot of us suffer like feeling dehumanized through the healthcare system, because throughout history, one of the main reasons that colonialism was able to be as successful as it was, was because colonialism sought to remove autonomy from our*

> *own bodies, and remove Indigenous people's autonomy to their bodies and to our own healthcare, and to our own treatment. (Y20)*
>
> *[A]s Indigenous people we are very resilient, but I also feel that, you know, we're humble and we don't really talk about our problems to non-Indigenous providers, whether they're doctors or psychiatrists, because sometimes it's hard to trust people. [...] be aware of Indigenous traumas and just to not make them feel like it was their fault or that there's something wrong with them, [...] be a good sounding board for them, to help, and to know that it is okay to get help. It doesn't make you weak. (Y167)*

Theme 3: relationships with healthcare providers

Relationships are particularly emphasized within Indigenous culture. The participants often spoke about relationships as either a strength or a barrier to their success in the transition process. Not all the youth had long-term relationships with their pediatric healthcare team, but several did. While positive relationships with healthcare providers were highly valued by all the research participants, it also made it challenging for some of the youth to move into adult care and begin developing new relationships. One of the youth explained this dynamic:

> *It's a big change to go from seeing the same team you've seen for like 16 years to another team and having to explain [...] So then to go from like familiarity to also a new world, it's just like it definitely takes some time, and some care and some patience. (Y197)*

Healthcare providers also spoke about how building long-term relationships with their patients was beneficial for positive health outcomes. When youth and their caregivers were asked how healthcare practitioners could assist with their successful transition, many noted the benefit derived from healthcare providers that put effort into listening to their needs and an understanding of the difficulty of the transition.

Several of the youth also found Indigenous representation on their healthcare team and Indigenous specific healthcare clinics as having a positive impact on their well-being. A Two-Spirited youth who had typically avoided healthcare services spoke about how receiving counselling from someone who was also Two-Spirited had a positive impact on their overall mental health and wellbeing:

> *But two years ago I ended up reaching out to find a counselor, and the thing is, they nailed it with the counselor, because this guy was also two-spirited. He had a similar path, and then kind of similar – he was so similar to me, and I finally felt like I would be able to unload my heavy onto someone who could handle it, and who like – because a lot of times I don't – I don't talk about what's going on with me, or any situation, because a lot of it's heavy, and unless you are mentally and physically and spiritually prepared to hear it and hold it, I usually have a good sense of character, judgment of character, on who is able to do that. (Y171)*

Another youth shared a similar perspective:

> *I like that I have a physician who knows about Indigenous stuff. And their clinic also includes Indigenous wellness and healing, so like they always have sage burning, and that just makes me feel really welcome there, and makes it – like I feel comfortable going there, so obviously that makes it a lot easier for me to follow up with appointments if I'm willing to go there and like meet with him. I know he's a nice guy. (Y04)*

Several healthcare providers also noted that because of their long-term relationships with youth, they may choose to come see them when they have an acute issue. One healthcare provider spoke about how some youth struggle with the transition and making it to their appointments which may result in them losing their space in the adult healthcare system. Some continued to see their pediatric care providers even into adulthood. One healthcare provider explained:

> *We have been working for some of our really complex kids to do that transition, where I help transition them to an adult physician, a family doctor, and then the family doctor helps link them with the adult services. But it's very dependent on those kids being able to make it to their appointments, so we've had some success, and like youths, they still will come back to me at 20, 21, 23 and they will contact me and be like, "I have this health concern, and I don't know how to address it." And then I will help them navigate what their options are in the adult world. I feel like the transition never fully happens. If they had a good relationship with me, they'll keep coming back if they get stuck. (HCP02)*

Overall, youth often just wanted someone to talk to and feel less alone in their transition.

> *I think just that mental health support, or like yeah, like a social worker to talk to or something, would be a lot – really helpful. Especially with the transitions, because it's just like scary, and you're on your own. (Y197)*

Theme 4: embedding indigenous worldviews into healthcare services

Many of the research participants noted that Indigenous cultural practices, teachings, language, and worldview was a protective factor for their overall wellbeing and could be beneficial for supporting a successful transition. One of the recurring subthemes was the importance of kin and familial support in Indigenous communities and worldviews, which was not always valued or taken into consideration by non-Indigenous healthcare providers and systems. One of the youth noted that for Indigenous people, these relationships are often critical systems of support:

> *One of the challenges I found transitioning from adult to – from pediatric to adult healthcare was the idea that like for me, like all of a sudden, I should be alone in making all my decisions, and I should be alone coming to appointments and stuff. Not that anyone, except I guess with the pandemic, when I really couldn't bring any support, but [healthcare providers] looking at the patient as like a singular individual instead of like part of a community and a family, that I think as Indigenous people. I know that was my biggest fear [...] going into adult healthcare was like I couldn't bring my mom to appointments anymore, which I still do, and luckily most of the time they're okay about that. (Youth Talking Circle Participant)*

Participants also spoke about how they rely on traditional healing practices such as prayer and medicines to support them and their families, as one caregiver shared:

> *And for me personally, I use a lot of prayer to find those supports. If I feel lost in finding them, then I light tobacco and I pray to our ancestors to help me find those supports. And I've always found that it really works. (CG18)*

A healthcare provider noted the importance of professional training to better understand the use of traditional medicines among their patients with chronic health conditions.

> *There needs to be options for, traditional medicine and that as well, for that transition there, and I think there needs to be a way to somehow harmonize that. I mean, from – first, from my perspective, I'm a very – obviously very medication focused professional, because that's my expertise, but in the same way, when I went through schooling, every time we approached any type of disease, condition, we always went over, "What are our non-drug methods to help this?" [...] I guess our more medicine focused or medication focused as long as with also a person's faith, belief system, or traditional or family ways there as well. So that's one thing I'd like to see. We do have an Indigenous health liaison here in the hospital, and yeah, it's just the way to kind of know how to harmonize those – those two approaches. (HCP11)*

A caregiver interviewee also reflected on the importance of incorporating both Western and traditional healing into the healthcare system:

> *We did try traditional healing methods, but I think that it has to be a combination of both Western and traditional healing methods. Because in today's society, you can't go one way or the other. It has to be both. That has been my experience. (Caregiver Talking Circle Participant)*

Theme 5: youth assuming new care responsibilities

While a small number of youths interviewed reported that they did not find their transition into the adult healthcare system overly stressful, many reported challenges and barriers. The pediatric care system differs from the adult healthcare system, and becoming an adult can come with other challenges as well.

> *For youth who are turning 18 even without a chronic health condition, Indigenous youth, especially if they have involvement with different systems, like Children's Services or things like that—what they're entitled to or their benefits change the structure, and all of their supports change when they turn 18, so it's a lot to manage. And the fact that the adult healthcare system is not more proactive about connecting with them means that if [the youth is] overwhelmed, which is likely, because there's a lot going on, that nobody will make sure that that connection is maintained when they're dealing with a lot of different stuff at once. (HCP06)*

Some of the biggest challenges the youth experienced were the newfound responsibilities they had to take to manage their health in addition to other responsibilities such as attending post-secondary education and/or working. Overall, many of the youth found the transition intimidating as they were now solely responsible for making critical healthcare decisions as one youth expanded on:

> *I would also say for youth, like you are in charge of your own health, and I know that's scary. Because I'll be honest, I did not want to turn 18, purely for that reason, like multiple places of how my mom could still like sign off on surgery if I needed surgery. Just that idea that I now need to sign the waiver,*

> *even if I actually agree with it, scared me. So it's kind of like letting yourself take time of realizing you are in charge of your own health, and you've got to kind of decide what you want and how you want to move forward, but you can also advocate for yourself. (Y15)*

Our data indicates that participants were not well prepared for their transitions (some described it as "nerve wracking" and "rocky"). Good communication from health care providers, preparation from health care providers, and involving the family (not just the youth patient) were seen as facilitators to good transition.

> *I think some support that would have helped me with the transition, if there was any, would be I guess literacy and how the health system, the healthcare system works, and what you need for it, and what is and isn't covered, I guess. What you do and don't need insurance for, ...I think because that's something that where the big part [of the] transition was needing insurance but not knowing how to go about getting it on your own. (Youth Talking Circle Participant)*

Some caregivers and healthcare providers spoke about how this newfound independence was at times difficult to watch due to the potential negative health outcomes:

> *But we've had to kind of like step back and let her make these decisions and let her find these resources on her own. But the hardest thing that we've had is getting her to take her meds, because she's an adult, she should be responsible for her health. She should be taking these medications. And we've tried everything. Her clock, timers, yelling at her, phoning her, texting her, everything, and we still cannot get her to take her life enhancing medication, no matter how many ways we put it. (Caregiver Talking Circle Participant)*

Like many of the caregivers interviewed in this study, although the youth took on more responsibility, for many of the youth, their caregivers remained involved in ensuring their healthcare needs were met. Several of the youth relied on family members to assist them with advocacy when facing challenges in accessing healthcare.

For some youth, there were detrimental health consequences resulting from the avoidance of healthcare and/or not adhering to their care plans, as explained by one of the youth participants:

> *When I got sick, after a bit of me getting better in remission, I stopped taking my medication and I wasn't supposed to. [...] I think I saw my doctor for a whole year, that year, and she told me, "Take your medication, and you will not end up on dialysis. Take your medication." And for a whole year I didn't listen. I didn't take my medication, and I drank. (Y16)*

Participants in all categories noted the critical importance of healthcare providers in the adult healthcare system working with Indigenous youth with pediatric onset health conditions to be mindful of the learning curve of entering adulthood. The newfound freedom associated with becoming an adult often caused new and additional life stressors that could impact their ability to make their healthcare a priority. One of the youth participants explained:

> *I don't know anyone who, from the span of turning 17 to 18 suddenly has it all figured out. Like we need a lot of help still. Because sometimes our parents have been managing this stuff for us for a while, and everybody's at a different level in what they know and what they're managing. So just be willing to, if you're an adult doctor, like still give us some of the care that you would as like a pediatric client. [...] So, I just wish we were given a bit more grace, you know, like a bit more space to get it figured all out, and if we mess it up, it's not because we're trying to sabotage our health or we're young and stupid. (Y04)*

Recommendations

From a solution-oriented approach, the interviews and Talking Circles sought recommendations on how to improve the transition from pediatric to adult healthcare services for Indigenous youth with chronic health conditions. Participants emphasized that it is critical that programming and services for this population build on the strengths and resiliency of Indigenous youth. Many participants noted that enhanced social and peer supports would be beneficial for youth, and for their primary support networks. Several caregivers also wanted a space to connect with others who were in a similar position to themselves. The youth wanted the opportunity to connect with other Indigenous youth who had chronic health conditions. Several of the youth reported feeling alienated from their peers who did not have the same healthcare considerations shaping their decisions. Another common recommendation was programming that helped older Indigenous youth develop skills to navigate the healthcare system and general health literacy about their diagnosis.

> *I think the successes are having the youth transfer successfully, so make the connections in the adult system, and make sure that they understand how to navigate and how to get access to that system when*

> *they need it. And then making sure that they had awareness of what they could use their healthcare treaty status for, like what sorts of services or supports are available to them, because there's lots that they don't know about that they don't take advantage of. So, making sure that they were aware of those things and were able to utilize it. (HCP06)*

Youth participants similarly mentioned that they were not aware of what types of services or medications would be covered by their Treaty status, which would have been helpful:

> *I think when I paid my first – when I had to pay my first like prescription, it was really weird because I didn't know that well, things weren't covered by status card, or places don't accept it. (Youth Talking Circle Participant)*

In addition, numerous participants noted that it would be helpful to implement programming that assisted youth to develop life skills that could influence their well-being such as identifying social services, accessing disability or social assistance benefits, or how to find housing. Specifically, there was an interest in on-reserve programming that was designed for the needs of older youth that incorporated mentorship and support. As one youth noted, this could be beneficial to ease the transition period:

> *I was just saying that just the guidance, like so it's not just like your kind of like thrown off the deep end and told, "Like figure out how to swim." [Laughs] (Youth Talking Circle Participant).*

The recommendations also targeted systems level changes that were needed in response to the challenges and barriers discussed above. Most of all, there was a desire for non-Indigenous healthcare practitioners to be better informed about Indigenous worldviews and some of the difficulties that Indigenous youth face in accessing healthcare that are often unique on-reserve. There was also a desire for adult healthcare practitioners to understand the challenges of the transition process that are specific to this age group. Most of all, youth and their support network wanted a healthcare system that listened to their needs with practitioners that were interested in developing long-term relationships.

Discussion

A growing body of research has demonstrated the mental and physical health consequences for youth with chronic health conditions that occur when transitioning from pediatric to adult healthcare systems [1, 5, 9, 10, 31]. To date, there is an absence of studies on this transition that are specific to Indigenous youth. The findings from the present study found that many of the barriers faced by Indigenous youth included those previously reported among non-Indigenous youth [1, 5, 9, 10, 31]. However, for Indigenous youth, the stressors associated with transition were often exacerbated due to structural inequality such as lack of services available on reserve, lack of access to reliable internet or phone to make appointments or follow up with healthcare providers, and/or competing priorities due to limited financial resources.

Many of the youth and their parents noted that the consequences of intergenerational trauma impacted their health and well-being. Several of the youth or their parents struggled with substance use, which made it difficult to prioritize their healthcare. Historical trauma is a form of intergenerational trauma that is a direct result of a long and ongoing history of systemic oppression, and is defined as "a cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences [36]." Unresolved historical grief and intergenerational trauma has been tied to increased substance use and greater lifetime exposure to trauma [36].

Although many of the youth and their caregivers have significant stressors in their lives tied to colonization, they also demonstrate resiliency and possess strengths that could be built upon to ensure a successful transition. Resilience includes factors that can contribute to an individual's ability to respond to life challenges, recover from challenging conditions, increase well-being and decrease health risk factors [37]. Indigenous Peoples and communities are resilient, as demonstrated by the preservation and revitalization of Indigenous languages, cultural practices, knowledge systems and traditional teachings [37, 38]. A systematic review of studies examining resilience among Indigenous youth identified three common themes that contributed to their resilience: the process of cultural continuity; community and family ties; and empowering programs for Indigenous youth [37]. The present study found similar strengths from community and family ties as well as connection to Indigenous cultural practices, languages and teachings. It is important that transition services and programming take a strengths-based approach that build on the demonstrated strengths of the youth, their families, and communities and be Indigenous led [39]. Indigenous youth specifically demonstrate resilience as a means of survival and healing [37], which is often through connecting to their culture, language, and the land [40–42].

Many of the participants were dedicated to ensuring future generations have improved access to healthcare services and mentorship in their community that incorporated Indigenous worldviews and cultural practices. For example, two of the youth participants worked as nurses. For many of the participants, Indigenous representation among the healthcare workforce was important for building trust with their healthcare providers as well as the larger healthcare system. Studies globally have similarly found that Indigenous people would like to see more representation of Indigenous healthcare practitioners. A strong Indigenous workforce in healthcare settings can have a positive outcome on healthcare outcomes [43].

It is not solely the responsibility of Indigenous youth, their families, and communities to ensure successful transition from pediatric to adult healthcare services. For example, there is critical work that must be done within healthcare systems to address systemic racism and discrimination [44–46]. There were several systems level recommendations provided by the research participants, most commonly the need for healthcare providers to be better informed about colonization and the legacy of residential schools and the impact on healthcare [47–49]. Moreover, it was also important for healthcare providers to be knowledgeable about Indigenous worldviews, medicines, and cultural practices. The healthcare system generally could better incorporate supports specific for Indigenous patients in recognition of the additional structural barriers to accessing healthcare services [43].

Healthcare equity requires appropriate resources according to need as well as addressing differential treatment arising due to systems level and individual factors, such as systemic racism and discrimination [48]. Systemic and individual racism also contribute to healthcare inequities of Indigenous Peoples [45, 46]. Recent studies in Alberta, Canada found that two-thirds of surveyed physicians have implicit anti-Indigenous biases [50] and that emergency department staff triage First Nations people differently than their non-Indigenous counterparts [51]. In 2015, the Truth and Reconciliation Commission of Canada released a series of Calls to Action to address the legacy of residential schools and advance the process of reconciliation in Canada [44]. The Calls to Action for health include the recognition of previous government policies as directly impacting the health of Indigenous Peoples in Canada and a call to close the healthcare gaps between Indigenous and non-Indigenous peoples [44]. Call to Action 23 calls on all levels of government in Canada to increase the number of Indigenous people working in the healthcare system as well as ensuring retention of Indigenous healthcare providers in Indigenous communities and ensuring cultural competency among healthcare professionals [44].

This study has some limitations. The data was drawn from participants residing mainly in the province of Alberta, with collaboration from a single Indigenous community and may not reflect the lived experience of transition-age youth and their caregivers in other provinces or communities. Youth having a broad range of healthcare conditions were included, which improves generalizability but may not capture nuances of specific health conditions. Data collection was conducted during the COVID-19 pandemic, which made recruitment difficult and may have inadvertently excluded participation of some individuals. Strengths include the community-based participatory approach with strong engagement and guidance from our Community Advisory Committee.

Conclusion

To our knowledge, this is the first study to describe the unique needs of Indigenous youth with pediatric onset chronic health conditions who are transitioning into the adult healthcare system. From a strength-based perspective, we found that these youth benefited from having access to Indigenous worldviews and culture during their healthcare transition. Likewise, having access to providers that were either Indigenous or provided culturally safe spaces was a source of support. However, these youth also faced structural inequities and intergenerational trauma that made the process more difficult. Community-based, Indigenous-led programming that would help youth navigate the healthcare system, develop their health literacy, and connect with other youth facing similar challenges was viewed as potentially being helpful. Our team, including CAC members, has developed a structured Indigenous Patient Navigator service for transition-age youth that will build on the findings from this work.

Abbreviations

CAC	Community Advisory Committee
CBR	Community Based Research

Supplementary Information

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Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.
Supplementary Material 5.

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Authors' contributions

AM conceptualized the study, developed the study design and methodology, secured funding, provided supervision, and substantively revised the work. MG analyzed and interpreted the data and wrote the original draft. AC (Chappell) provided study coordination, acquired, analyzed and interpreted the data, and substantively revised the work. KD analyzed and interpreted the data, and substantively revised the work. RL (Lightning) developed the study design and methodology, and interpretation of data. LL developed the study design and methodology, and interpretation of data. AC (Crier) developed the study design and methodology, and interpretation of data. BDJ acquired and provided interpretation of data. AT developed the study design and methodology, and interpretation of data. BG developed the study design and methodology, and interpretation of data. RL (Littlechild) developed the study design and methodology, and interpretation of data. JL developed the study design and methodology, and interpretation of data. AJ developed the study design and methodology, and interpretation of data. PR developed the study design and methodology, and interpretation of data. MC developed the study design and methodology, and interpretation of data. RO conceptualized the study, developed the study design and methodology, provided supervision, and substantively revised the work. All authors have approved the submitted version and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Data availability

This study adheres to the principles of Ownership, Control, Access, and Privacy (OCAP™) and will not make the interview data publicly available.

Declarations

Ethics approval and consent to participate

The study was approved by the University of Alberta Health Research Ethics Board (Pro00095750). All interview and Talking Circle participants provided informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Publisher's note

Andrew Mackie Andrew is a white Settler of European and white South African descent. He lives on Treaty 6 territory and has two adolescent children. He is a physician, practicing pediatric cardiology. From the healthcare provider perspective, he has seen the consequences that adolescent Indigenous youth face when they experience a lapse in specialty care, and is motivated to finding ways to provide culturally sensitive care to improve the transition experience for all youth.

Mandi Gray Mandi is a white settler from Treaty 1 territory (near Winnipeg). She currently resides in Toronto. Since 2008, much of her work has been dedicated to supporting the community work of First Nations women, girls, and gender-diverse people. She is currently an assistant professor at a small university in Ontario.

Alyssa Chappell Alyssa is a white settler from mixed European descent, including English, Irish, Norwegian and Scottish. She is grateful to be living and working in Treaty 6 Territory, in amiskwacîwâskahikan (Edmonton) with her partner and extended family. Her background is pediatric nursing and she completed her undergraduate studies at the University of Alberta. She has been fortunate to work with the community of Maskwacis on this work since 2020.

Kira Dlusskaya Kira is a first-generation immigrant who came to Canada from Russia as a child and grew up in Edmonton, Alberta, on Treaty 6 territory. She completed her undergraduate studies at the University of British Columbia (unceded Musqueam territory) and her Master's degree at the University of Alberta. She is grateful to call Łue Chok Tuê (Cold Lake) home, along with her husband and extended family.

Rick Lightning Rick's name is Wapî-maskwa (White Bear). He comes from the Buffalo Child family (Albert Lightning) and the Bear Hills people of Maskwacîs, in Treaty Six territory. His wife, Inez Lightning (Yellow Bird Woman), is Anishinaabe. Rick has 10 children, 37 grandchildren and 10 great-grandchildren. He is Nêhiyaw (Cree) and lives his life accordingly. Rick is a third-generation residential school survivor.

Larry Listener Larry Listener comes from Metîs, French and Nehiyaw (Cree) descent. His spirit name is Kinosew (Fish) and it was given to him by his grandparents. He lives in Maskwacîs with his wife of 49 years, Winona (White Woman) who is a descendant of the Blackfeet Nation. Together they have 5 children, 8 grandchildren and 2 great-grandchildren. Larry loves being out on the land, hunting, picking medicines and passing on his teachings. He is a cultural person who enjoys dancing Golden Age Buckskin at local powwows, singing and playing handgames. He is a second-generation Residential School survivor.

Arrol Crier Arrol's name was Okîmâwyapîwîyan. He was a strong, Nêhiyaw (Cree) man from the Nipisihkopahk (willow grove) people of Maskwacîs, in Treaty Six Territory. He lived his life guided by the Nehiyaw mâmitonehicikan (Cree way of thought) passed down to him by his father, Louis P. Crier.

Barbara Dumigan-Jackson Barbara Dumigan-Jackson is a nêhiyaw iskwêw (Cree woman) from Onihcikiskwapin "Saddle Lake Cree Nation" and ka-miyosicik kinosewak "Goodfish Lake First Nation" in Treaty 6 Territory. Barbara Dumigan-Jackson comes from a very cultural upbringing in the nehiyaw (Cree) traditional community. She incorporates cultural knowledge into her home, workplaces, hobbies, and everyday life. Barbara is a mother of 3, Indigenous artist, Indigenous Researcher and educator. Barbara strives on being rooted within her Cree culture, teachings, motherhood and the land. Being rooted provides her with a sense of belonging and helps her remember who she is and where she comes from as nêhiyaw iskwêw (Cree Woman) and as nêhiýaw people we are people of the land.

Audrey Thomas Audrey's nehiyaw name is wap pehew iskwew (white prairie chicken woman). Audrey is a proud nehiyaw iskwew from Sturgeon Lake Cree Nation on Treaty 8 territory. Audrey is the proud mother of 5 children and 4 grandsons.

Bonita Graham Known to friends, family and colleagues as Bonny Graham. My homeland is Thunderchild First Nation in Central Saskatchewan. I am a descendant of Chief Piyesui-Awasis. Currently, I live in Wetaskiwin, AB with my husband and together we have raised our 4 daughters and now enjoy 11 Grandchildren. As a product of the 60's scoop, I am endeavoring to learn about my Culture, Traditions, Teachings and Spirituality. I am an advocate for the implementation of all the TRC recommendations and volunteer on committees that endorse and promote TRC recommendations. I have been a Nurse for 44 years and continue to work full-time. In my spare time, I volunteer for community organizations in several capacities. My heart is in advocacy for the vulnerable and less privileged. It has been my honour to work in the community of Maskwacis since 2006.

Randy William Littlechild Born at the Charles Camsell Hospital in Edmonton to a Cree woman form Ermineskin First Nation. Because I was a sixty Scoop survivor, I grew up on a farm till I was sixteen, then made my way to Hobbema to become familiar with my relatives I never received a cree name. I am married and have two adult children and 2 grandchildren from my wife's daughter. I am proud of my heritage and currently involved in the administration of Health Services for the Maskwacis people.

Joshua Lightning I am Joshua Lightning, a proud plains Cree First Nation from Treaty 6. I am grateful to have been helping the Ermineskin Cree Nation building homes on reserve, getting schooling and training. I am currently working in oil and gas industry doing Remediation and Reclamation work on reserve. I have 2 kids that needed the children Stollery NICU help from birth and are growing well because of the great work Stollery was able to give us. It brings me great sense of pride to be apart of this study and bring benefits to the community.

Azure Johnson Plains Cree and resides on the Pigeon lake Indian Reserve 138A in Treaty 6 Territory, her ceremonial name is 'Mahekan - Wolf' and she is the proud daughter of late Janet Fox. She is the 4th and last generation to attend Indian Residential School. Azure's educational and professional background has provided extensive experience in the areas of the Criminal Justice System, Child & Family Services, Education and Mental Health with specialized training serving Indigenous Peoples suffering from Addictions due to intergenerational effects from Indian Residential School. Her focus has been building partnerships in the contest of a Treaty Relationship.

Patricia Rain My rightful name is White Thunderbird Woman (Patricia Rain). I am an Elder from Nipisihkopahk (Samson Cree Nation). I am a proud Cree speaking woman. I have 3 beautiful daughters and 13 grandchildren. I am very happy to announce I will be a chapan next year. My first great grandchild. I live and work in my community of Mimiw Sakahikan. My goal in my golden age is to help my community in any way I can. To teach my children our traditional way of life. I was married to a non-native who controlled my beliefs for many years. I was not allowed to attend ceremonies or speak my language for the duration of our marriage. I have been divorced for many years and I am now free to go back to my traditional way of life. I am a golden age traditional dancer, and I travel to pow wow all summer. I am a proficient Cree speaker and teaching my grandchildren the language. I am a second-generation residential school survivor. I am a certified teacher, and I have my Master's diploma in leadership and Administration from the University of Lethbridge. I do believe in getting an education, so I have encouraged my grandchildren to further education. Two of my grandchildren are in university. My focus is to bring awareness and understanding of our Cree way of life to anyone who is interested but especially the youth in our communities.

Maxine Cutarm Maxine is from Pigeon Lake, Ermineskin Band Member of Maskwacîs, Alberta. She is 61 years old and has lived in Pigeon Lake for most of her life. She has 1 son and 4 granddaughters. She loves to dance round dance and powwow. Maxine is a second-generation residential school survivor.

Richard Oster Richard's ceremonial name is Wâpastim (White Horse). He comes from mixed European descent, including Danish, Scottish, German, Austrian and Ukrainian. Since birth, he has called Treaty Six Territory and Métis North Saskatchewan River Territory, in Alberta, Canada, home. His family has lived in this area for four generations and he continues to live here with his wife (who is of Cantonese Chinese descent) to raise his two children. He focuses on a strengths-based and partnership approach, building specifically on Indigenous ways of knowing and the resilience and strength within communities, as opposed to using a deficit-focused western lens which tends to dominate the field.