





CJC Open 5 (2023) 661-670

Original Article

Heart Health Begins With Community: Community-Based Research Exploring Innovative Strategies to Support First Nations Heart Health

Sahr Wali, PhD,^{a,b} Justice Seidel, MIR,^c Greg Spence,^d Lynne Innes, BScN, MN, MBA,^d Elaine Innes, BScN, MD,^d Anne Simard, MHSc,^e Angela Mashford-Pringle, PhD,^f Isaac Ssinabulya, MBChB, MMed,^{g,h} Joseph A. Cafazzo, PhD, Peng,^{a,b,i} and Heather Ross, MD, MHSc, FRCPC^{e,j,k}

^a Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada; ^b Centre for Digital Therapeutics, Techna Institute, University Health Network, Toronto, Ontario, Canada; ^c Minomathasowin Healthy Living Public Health Department, Weeneebayko Area Health Authority, Moose Factory, Ontario, Canada; ^d Weeneebayko General Hospital, Weeneebayko Area Health Authority, Moose Factory, Ontario, Canada; ^d Ted Rogers Centre for Heart Research, University Health Network, Toronto, Ontario, Canada; ^f Waakebiness-Bryce Institute for Indigenous Health, Dalla Lana School of Public Health, University of Toronto, Ontario, Canada; ^g Uganda Initiative for Integrated Management of Non-Communicable Diseases, Kampala, Uganda; ^h Uganda Heart Institute, Mulago National Referral Hospital, Kampala, Uganda; ⁱ Institute of Biomedical Engineering, University of Toronto, Ontario, Canada; ^k Peter Munk Cardiac Centre, University Health Network, Toronto, Ontario, Canada; ^k Centre (University Health Network, Canada)

ABSTRACT

Background: Indigenous people have displayed their strength through their holistic practices and spiritual connection to the land. Despite overcoming the impact of discriminatory and disempowering policies within Western institutions, Indigenous people continue to experience a higher risk of cardiovascular disease, compared to the general population. To move toward improving Indigenous health outcomes, researchers need to work in partnership with communities to develop heart health strategies centred on their experienced barriers and sources of healing. We conducted a community-based explorative

RÉSUMÉ

Contexte: Les peuples autochtones tirent une grande force de leurs pratiques holistiques et de leur lien spirituel avec le territoire, et même s'ils ont surmonté les répercussions des politiques discriminatoires et marginalisantes des institutions occidentales, ils présentent encore un risque de maladies cardiovasculaires supérieur à celui de la population générale. Afin d'aider à améliorer la santé cardiovasculaire des Autochtones, les chercheurs doivent travailler avec les communautés pour mettre en place des stratégies qui tiennent compte des obstacles en matière de soins de santé et des méthodes de guérison

Indigenous people have displayed their strength through their holistic practices and spiritual connection to the land. The compassion and connectedness embraced within Indigenous culture has been shown to promote a healthy way of living, compared to the sedentary lifestyle of Western communities. In the face of adversity, Indigenous people have maintained their cultural traditions as a form of resilience. However, given that many discriminatory constructs and systemic barriers remain within the healthcare system, Indigenous people

Received for publication January 23, 2023. Accepted June 27, 2023.

Corresponding author: Dr Sahr Wali, Centre for Digital Therapeutics, Toronto General Hospital, University Health Network, R. Fraser Elliott Building, 4th Floor, 190 Elizabeth St., Toronto, Ontario M5G 2C4, Canada. Tel.: +1-416-340-4800 x4765.

E-mail: sahr.wali@mail.utoronto.ca See page 669 for disclosure information. have been found to experience a higher burden of poor health outcomes.^{2,5} Specifically, with 4.3 million people in Canada currently living with cardiovascular disease (CVD), Indigenous people have been found to be among the highest-risk groups for CVD-related prevalence and mortality.^{2,5,6} Recognizing that health surveillance systems in Canada may not be accurate or representative of all Indigenous populations, recent studies display significant evidence connecting the disproportionate burden of CVD-related risk factors among Indigenous peoples to the disparities in their social determinants of health,^{2,7-11} These determinants include many fundamental human necessities, such as access to housing, water, food security, healthcare, and income generation.^{12,13}

With several complex and interdependent factors contributing to the disparities in Indigenous health outcomes, the underlying roots responsible for these conditions have been

study in Moosonee, Ontario to explore the local community's needs and priorities regarding heart health and wellness.

Methods: A convenience sample of community members and healthcare professionals were invited to participate in a sharing circle. Qualitative data were analyzed using conventional content analysis and the Indigenous method of *two-eyed seeing*.

Results: Eight community members and 5 healthcare professionals participated in the sharing circle. Four dominant themes were identified: (1) heart health is more than metrics; (2) honouring our traumas; (3) destigmatizing care through relationship building; and (4) innovative solutions start with community. With the history of mistreatment among Indigenous people, strength-based solutions involved rebuilding clinical relationships. To bring care closer to home, digital health tools were widely accepted, but the design of these tools needs to integrate both Western and Indigenous approaches to healing.

Conclusions: Indigenous health upholds the physical, emotional, psychological, and spiritual needs of an individual as being of equal importance. To improve community heart health, strategies should start by strengthening broken bonds and bridging multiple worldviews of healing.

associated with the impact of European colonization. 12-14 Harmful practices, such as the explicit banning of cultural practices, the forced removal of Indigenous children into residential schools, and the dislocation of communities to reserve areas or road allowances, collectively dismantled the cultural foundations of Indigenous peoples within what was perceived as the "evolving" Western society. 10,13-15 The Truth and Reconciliation Commission of Canada (TRC) Calls to Action and Royal Commission on Aboriginal Peoples (RCAP) Recommendations have documented the various injustices to Indigenous peoples that have been carried out and have reported the inherent need to better support culturally safe care. 13,16 However, despite these reports and calls for systemic change, many colonial constructs continue to oppress Indigenous peoples within the current healthcare system. 13,14 From poorly funded care facilities to the abiding level of racism within the delivery of care services, Indigenous communities face an array of barriers that make access to culturally safe care unlikely to become a reality. 1,17,

To begin to move toward a path of reconciliation that fosters Indigenous well-being, many studies emphasize the importance of first identifying and understanding the unique needs and challenges faced in the community. ^{15,18} Fontaine et al. highlight that, within this understanding of community needs, identification of how the process of healing is defined for each community is also important. ^{18,19} By contrast to Western biomedicine, in many First Nations populations, heart health is approached in a holistic manner, whereby the physical, emotional, psychological, and spiritual needs of an individual are held to be of equal importance. ^{18,19} Given that the current healthcare system focuses predominantly on biomedicine, many of these Indigenous values and definitions

traditionnelles. Nous avons réalisé une étude exploratoire en milieu communautaire à Moosonee (Ontario) dans le but d'explorer les besoins et les priorités de la communauté locale en matière de santé cardiovasculaire et de bien-être.

Méthodologie : Des membres de la communauté et des professionnels de la santé ont été invités à participer à un cercle de partage. Les données qualitatives ont été analysées au moyen d'une analyse classique et de la méthode autochtone dite à double perspective.

Résultats: Huit membres de la communauté et cinq professionnels de la santé ont participé au cercle de partage. Quatre principaux thèmes ont été abordés: 1) la santé cardiovasculaire va au-delà de ce qui se mesure; 2) il faut tenir compte des traumatismes; 3) il faut déstigmatiser les soins en nouant des relations et 4) les solutions novatrices doivent reposer sur la participation de la communauté. En raison du passé de maltraitance envers les peuples autochtones, les solutions axées sur les forces devaient permettre de restaurer la confiance envers les soins cliniques. Les outils de santé numérique, bien adaptés aux besoins de la communauté, ont été largement acceptés, mais ils doivent intégrer les méthodes de soins occidentales et autochtones.

Conclusions: Selon la vision autochtone, la santé repose en parts égales sur les aspects physiques, émotionnels, psychologiques et spirituels d'une personne. L'amélioration de la santé cardiovasculaire des membres de la communauté passe donc avant tout par des stratégies qui permettent de recréer les liens qui ont été brisés et qui intèrent plusieurs visions thérapeutiques.

of health often fail to be integrated within the delivery of heart health strategies. ¹⁹ Given this situation, to better support the process of healing within the context of an Indigenous community's cultural identity, many studies recognize the value of working in partnership with communities for the development a locally informed heart health strategy. ^{13,20}

Given the importance of community engagement, community-based participatory research (CBPR) is used increasingly to support the production of knowledge in a manner that prioritizes the significance of lived experiences. On the center of a partnership to better understand community needs from the perspective of different cultural worldviews (ie, Western and Indigenous knowledge). Motivated by the strengths of CBPR and the need for culturally informed heart health strategies, this study sought to better understand how to support community heart health and wellness, by working in partnership with the First Nations community in Moosonee, Ontario.

Methods

Setting

Along the mouth of the Moose River lie the town of Moosonee and the island of Moose Factory, gateway to the Arctic and the homeland of the Moose Cree people. ²³ For centuries, Moose Factory has been a gathering site, with its relations extending to a diverse group of Indigenous and non-Indigenous peoples within the region. Although each community may differ in its unique culture and values, all of them are connected through a shared past of resilience. By

continuing to live with and striving to overcome the impact of discriminatory and disempowering policies within Western institutions, the Cree people have showcased their strength in the face of adversity. A consequential impact of living through racist policies and their impacts is the burden of carrying the generational traumas of the past into the inequitable conditions of the present. Further, as healthcare access is limited in the remote communities along the James and Hudson Bay (JHB) region, patients with chronic conditions, such as heart failure, often face a higher rate of mortality, compared to the general population.

Currently, the Weeneebayko Area Health Authority (WAHA) provides healthcare services to approximately 15,000 people across 6, predominantly Cree, communities (Moose Factory, Moosonee, Attawapiskat, Fort Albany, Peawanuck, and Kashechewan) in the JHB region. WAHA distinguishes itself by being a community-focused organization centred on providing optimum healthcare close to home. WAHA currently relies on 2 cardiologists, who visit 6 to 12 times per year, for in-person cardiac care. Apart from these visits, patients are required to travel over 9 hours to receive specialist care. To better support the community's heart health needs, within the limitations of their contextual environment, an opportunity exists for innovative care strategies to be introduced. 5,24

Study design

A community-based explorative study was conducted to assess the Moosonee community's needs and priorities regarding heart health and wellness. In many Indigenousbased studies, health research has often been conducted by external parties without proper consultation or partnership processes being in place. ^{21,25-28} This type of exclusionary research practice has often resulted in minimal health benefits and has been associated with instances of harm to the community.²⁶⁻²⁸ To better understand the significance of local context and empower the local First Nations voice, the principles from CBPR were leveraged throughout all study procedures. ^{20,21,26} Within the CBPR approach, a series of Indigenous research paradigms and methodologies also were utilized to respectfully engage with the community in a conversational approach. ^{21,28} Specifically, to honour the First Nations traditions of storytelling, community-based sharing circles were used as the primary source of data collection and the "nothing about us without us" tenet was embedded as the theoretical paradigm for this study. 26,28,29 This study was facilitated in adherence to Articles 9.1-9.22 stipulated in Chapter 9 of the Tri-Council Policy Statement on Research Involving the First Nations, Inuit, and Métis Peoples of Canada.

Researcher positionality

Across different disciplines of health research, integrating sources of reflexivity has been encouraged increasingly, to better identify the positionality of a researcher. By reflecting on an individual's roots—from where their history originates to how their current relations have grown—researchers are able to better understand how their beliefs and biases have influenced different aspects of the research process. The

authors of this paper have Afghan, Cree, Algonquin, Ugandan, French, English, and Italian ancestries. This collaborative team may come from diverse backgrounds, but we strive to embrace the culture and worldviews that have shaped our individuality to transform the delivery of culturally safe care. Given that Western research often characterizes population groups in a deficit manner, our team's goal is to leverage the value of culture and context to improve the health and well-being of communities that are most underserved.

Partnership building

Central to Indigenous CBPR is the establishment of ethical relationships built on trust and mutual learning. 13 A series of partnership efforts were initiated with the WAHA and the JHB communities. The team from the University Health Network (UHN), based in Toronto, used the Intervention and Research Readiness Engagement and Assessment of Community Health Care (I-RREACH) tool to ensure that respectful engagement strategies were utilized.³¹ As part of the I-RREACH tool's participatory consensus cycles, the UHN team first engaged the JHB Community Health Directors to explore the potential for project collaboration. With the support from WAHA leadership and the community health directors, a collaborative working group (CWG), comprised of WAHA staff and a local community elder, was formed to provide direction and oversight to the UHN team. Over the course of 3 years, the UHN team has facilitated a series of team meetings with the CWG to modify the study approach in relation to the community's changing priorities.

Using the guidance from the WAHA and the CWG, a research proposal exploring innovative strategies for heart health and wellness was codeveloped. This project initially was centred on the use of digital tools to support heart failure management, but local guidance modified the study objectives to broadly explore heart health in the community and the local perspective regarding the use of technology for care support. Recognizing the critical need to support local capacity-building, a local research assistant from the WAHA (J.S.) was hired to co-lead all project activities. The Indigenous method of two-eyed seeing, developed by Mi'kmaw Elder Albert Marshall, was specifically utilized to promote a strength-based approach of co-learning. 32 Two-eyed seeing has been defined as a metaphor for negotiating between 2 cultures. By learning to see the strengths of Indigenous knowledge from one eye, and the strengths of Western knowledge from the other, this reflexive approach to inquiry provides a conceptual framework to equitably embrace multiple perspectives within its own value. 32 This study was approved by the WAHA's Research Ethics Committee. The mayor's office of the town of Moosonee also was informed of all study activities.

Recruitment

From April 25 to May 11, 2022, a series of recruitment efforts were initiated with the use of physical and virtual posters. Physical posters were displayed within central stores and community centres across Moosonee. Virtual posters were also publicized on the official WAHA Facebook page and hospital board. Community members were able to call the study team to confirm their sharing-circle participation, or

they were able to directly visit the community centre on the day the sharing circle was hosted (May 11, 2022). The design and location of all posters were based on the guidance from the WAHA team and the local community to ensure their overall relevance and appropriateness. This study did not have any strict study eligibility criteria, as anyone with an interest in heart health was permitted to participate.

Data collection

Once the study proposal was approved by both the WAHA and the CWG, a community-based sharing circle was conducted with a convenience sample of Moosonee community members and healthcare staff. To ensure that the values and priorities of the Moosonee community were incorporated within the sharing circle, the UHN and WAHA team members worked collaboratively with a local elder (G.S.) to codevelop the sharing-circle guide and agenda. Elder guidance was used to include guiding questions related to traditional diets, lifestyle, and healthcare challenges. Items related to the sharing-circle venue, length, and recruitment strategy also were addressed throughout these collaborative discussions.

Before the start of the sharing circle, all participants were provided with an overview of the study objectives, to obtain informed consent. In alignment with the First Nations principles of OCAP (Ownership, Control, Access, Possession), participants also were provided with the opportunity to ask questions regarding the use, collection, and dissemination of their data. Participants who were interested in analyzing or receiving the core study findings were provided with a separate form to outline their contact information for the distribution of the study findings. Given the importance of equitable and transparent principles of knowledge ownership, the control and possession of all study records were determined per the guidance from the local team. Beyond these efforts, the UHN team aims to continue their collaborative engagement with the local Moosonee leadership to appropriately distribute the study findings beyond academic platforms. This distribution may include avenues of social media, radio, posters, and community events.

Once participant study consent was obtained, the local elder opened the sharing circle by introducing the space as a safe environment for discussion. Participants were reminded that in the circle, everyone was valued as equals and that individuals could participate by sharing their stories or simply listening, based on their personal preference. At the end of the sharing circle, a lunch from a local community vendor was provided to all participants. A community raffle also was conducted among the sharing-circle participants, with the prize of a knife set from a local hunting store.

Data analysis

With the consent of all community members, the sharing circle was audio recorded, deidentified, and transcribed verbatim using NVivo 12 software (QSR International). The sharing-circle transcript was analyzed using conventional content analysis, and the Indigenous method of *two-eyed seeing*. To facilitate the *two-eyed seeing* approach, all transcripts were analyzed independently by one member of the UHN team (S.W.) and one member of the WAHA team (J.S.). Collaborative analytic meetings were then held between the 2

Table 1. Participant characteristics

Characteristic	Community member	Healthcare staff
Sample size	8	5
Sex		
Male	2	0
Female	6	5
Ethnicity		
Indigenous	7	2
Non-Indigenous	1	3
Heart health history/ interests		
Heart condition	4	_
Interest in heart health	2	5
Multiple health conditions	2	_
Care challenges/interests		
Racism/discrimination	8	5
Cultural safety	6	4
Digital health & wearables	4	5
Clinical relationships	2	1

Values are n.

researchers (S.W., J.S.) to discuss the various Indigenous and Western attributes within the inductive analysis. Eakin and Gladstone's value-adding approach was also utilized to enrich the analytic interpretation of the study findings.³³ The process of value-adding has been used in qualitative research to challenge the evaluation of study data—in its ability to not only reveal knowledge, but also to reconceptualize what is already known.³³ Through this approach, study feedback can be interpreted at a more abstract level, to provide a better understanding of the realities of a community's evolving contextual narrative. To implement this method within the data analysis, each study team member (S.W., J.S.) leveraged the memoing technique to contextualize their reflective notes. 33 After a total of 4 analytic discussions, the core themes generated by the study team were reviewed individually by the local community Elder (G.S.) for member checking.

Results

A total of 8 community members and 5 healthcare professionals (HCPs) participated in the community-based sharing circle (Table 1). Four dominant themes related to the state of heart health and wellness were identified: (1) heart health is more than metrics; (2) honouring our traumas; (3) destigmatizing care through relationship building; and (4) innovative solutions start with community (Table 2). The first theme outlines the complexity of the heart health journey and the various contextual challenges that impact patient care management. The second theme describes the history of mistreatment of First Nations communities and the importance of using strength-based approaches to move toward restoring heart health. The third theme recognizes the significance of community and family relationships, and the need to understand an individual's context in order to improve their health outcomes. Finally, the fourth theme builds on the value of empowerment and the need for health interventions to blend both Western and Indigenous approaches to wellness.

Theme 1: heart health is more than metrics

Within the Moosonee community, many participants shared the complexities behind their heart health journey.

Table 2. Summarized thematic findings

Theme	Subthemes ourney of heart health is complicated Diverse symptoms and abrupt diagnosis Strength in learning to live with condition Need for local care support Barriers to care management Burden of travel and desire for care closer to home Limited equipment and staff availability Acceptance of lack of care support available Food insecurity—inability to manage diet and health	
Heart health is more than metrics		
Honouring our traumas	 Food insecurity—inability to manage diet and health Broken promises lead to mistrust—sense of abandonment History of healthcare system exploitation Racism and discrimination within care services—fear for future generations Strength and taking control—true resilience of community Surviving residential school through connection with community Humour as resilience—Cree culture uses humour to soften care journey 	
Destigmatizing care through relationship building	Importance of family and community Community serves as avenue of reliable support through difficulties Valuing context and relationships Understanding the value of the individual Temporary physician locums lead to broken bonds Gender roles and competing family priorities "White coat" syndrome and weak patient relationships	
Innovative solutions start with community	Healthy habits and innovative solutions Taking control through self-care Digital tools can reduce care challenges Designing intervention with compassion Importance of community-informed customizations Empowering adoption through community-based education Bridging worldviews Importance of learning new ways of healing Holistic care blends Western and Indigenous approaches to wellness	

From the sudden escalation of symptoms to the relatively abrupt diagnosis of a heart condition, community members faced a diverse range of symptoms before they received any source of care support. Given the level of difficulty community members have faced in the past, a common trend was that individuals often minimized the severity of their symptoms, as they were either unaware of the seriousness or felt that waiting for symptoms to subside was easier than waiting for specialist treatment.

I didn't expect it. I thought I was a healthy type of person, like I wasn't active too much. I played some hockey and done some walking and stuff like that. But I started noticing things happening to me before I ended up getting the bypass. I was walking quite a bit before that, and I was wondering if it had something to do with that but [it] didn't. I would run out of breath as I was walking. I'd have to stop, and it would disappear. That feeling would disappear. And I started getting symptoms that were I guess classic to leading up to a heart attack like sore under the arms, sore under the jaw, which I didn't know at the time. (Community Member 1)

The reality shared by many community members involved their strength in learning to live with the challenges of their condition. Regardless of their diagnosis, community members recognized their weaknesses and fought to move forward to a better state. The primary concern that disempowered the community from managing their health involved the difficulty of travelling for care support. Whether this involved a 10-minute helicopter ride to Moose Factory or a 2-day trip south to Kingston, both of these options involved similar challenges, creating a significant need to bring care closer to home.

I fly in, and out [for] two-week periods and I come in, I work in the community to take care of a lot of the Elders, and I agree the determination and strength of this community is just outstanding. What you overcome in your own lifetime and for the medical issues that you have to deal with, you have to fly out most of the time . . . You spend a lot of time away from home. (HCP 1)

You do go through a lot, and it would be nice to see the hospital built on this side, so you don't have to helicopter or boat ride over to the hospital, spend months in Kingston having treatments through the thaw and the freeze. You know, the determination to get your health up to par and stay there is just astronomical. (Community Member 4)

One community member felt that the physical challenge of getting to a clinic was not worth the limited care received, as the current hospital did not have the resources to support the needs of their condition. This lack of resources included limited staff, lack of equipment, and poor hospital infrastructure (ie, lack of an elevator). In many cases, even after waiting long hours to be seen by a clinician, patients were either sent home or referred to a larger hospital.

Maybe someday we'll be lucky to have a hospital here, that's my prayer. And for me, it's really hard, difficult for me to go to Moose Factory because I have asthma—the stairs, no elevator. And then they [you] have to go up when you get off the boat, you have to walk up and it's difficult to walk up those stairs into the hospital. (Community Member 3)

All the beds were full and everything in Moose Factory. So, I went home, and I got up early in the morning, off and on I was awake in the night too, and the morning, I went to the hospital because I went

to the clinic and then sailing took me over to Moose Factory. So, I sit there and wait till two o'clock in the afternoon, those doctors were all busy. (Community Member 4)

Given these limitations, a sense of acceptance among community members was revealed, regarding the quality and the level of care services that could be provided, whereby the challenges of care access, to an extent, became normalized. One major factor that could not be dismissed involved the burden of food insecurity. Many community members and HCPs recognized the importance of managing their diet and lifestyle to prevent the worsening of their condition, but with healthy food options often costing over 3 times the regular cost of food, heart health management became unaffordable.

One of the things that I noticed after my surgery, the heart surgery was that when you go into the stores, you say, holy mackerel, they're killing us. When you look at what's in the store and what you buy. And I never thought of that before. Like, I eat everything. (Community Member 6)

Theme 2: honouring our traumas

Across the JHB communities, a long history of broken promises created a sense of mistrust regarding the health system. One community member shared that they felt abandoned by the health system, creating a level of confusion and stigma when the COVID-19 vaccine rollout occurred. With the history of experimentation on Indigenous communities, many Indigenous peoples were hesitant to receive a vaccine, as they felt their health was not being prioritized, but rather that they were being exploited.

Some people don't know we're here, but we are here. . . . We're just about 106 miles up the tracks, right? But we're here, we're here. (Community Member 2)

So, our area was one of the first places to get the vaccines, and there was a lot of hesitancy, and it was due to the lack of trust. A lot of people thought they were the experiment. (Community Member 5)

Recognizing the intergenerational impact of Canada's colonial past, community members shared how their mistrust of the health system was amplified by the current racism embedded within the delivery of care services. From dismissive clinical consultations to aggressive community encounters, Indigenous peoples continue to experience the unethical impact of racist behaviours. One community member shared their view that—despite Indigenous peoples having built the strength to defend themselves—for their grandchildren to have to experience the same emotional cycle was unfair.

I'm hoping that it goes away at some point because I don't want my grandchildren to know how that feels . . . Once I was coming back from a movie and four young men chased me and they said you're going to get it. And they used the word "squaw" [racial slur], and they ran. I didn't think I could run that fast, but I did run. I picked up a board that I see. I said come and get me then, and I would just be waving that board around. They turned round, backed off. Yeah. I sure hope they don't have to live with stuff like that . . . It just hurts me that people are still against us, the Indigenous people. I'm sorry. I don't know if I can carry on. (Community Member 1)

When discussing the cycle of discrimination experienced by Indigenous peoples, the abuse at residential schools was identified as the underlying root to many experienced traumas. Several community members indicated that the only way they survived residential school was through the hope of returning to their family and the land. These values of family and community were recognized as the core tenets behind the strength of Indigenous peoples. In reflection of these experiences, community members felt that in order to move toward a path of empowerment and reconciliation, clinicians need to recognize the past—not just as history but in terms of the generational impact on the present.

I went to residential school. I'm a survivor. I'd been going back and forth to residential school because my parents were hunters and they lived in the bush all year round doing their hunting ground, far from Attawapiskat, Ontario. That's where I was born and my parents lived there, I guess moved here when I was about 8 years old. (Community Member 7)

When I was there, I didn't know those things were happening. Some of my friends were abused, especially when they didn't go home on summertime (sic) when we go home to our parents. I really have a hard time when I listen to them sharing at that conference in Fort Albany. Took me weeks to get over it, what I heard. (Community Member 5)

While understanding the importance of honouring the past, many community members also shared their stories regarding the value of using humour as their source of resilience. In Cree culture, humour was found to be used commonly within everyday life to share good news and often to soften the obstacles of the care journey. To develop a meaningful heart health strategy, the community felt that both the hardships and triumphs of their experienced realities should be integrated.

So, I'm 70 years old. I had a massive stroke back in 2017, so in between 2017 [and now], I've lost a lot of gray matter. So, you see chunks laying around. Pick them up and push [them] up in the ear here. They'll find their way. (Community Member 1)

And now the last two years I've been going through a lot of stress, and I lost 50 pounds, which is good for my diabetes. I don't regret that . . . I had to get rid of my nice blouse and pants and anyways, it was still good. (Community Member 1)

So now I'm getting the bike. She's getting a scooter. And my other friend is trying to get a bike too, so they'll call us the bicycle mamas because we are going to be on the street. We won't be falling, and we even have a basket so we can go on a picnic or whatever [at] our speed (Community Member 6)

Theme 3: destigmatizing care through relationship building

Family and community are important within the Cree culture, and many community members shared that their determination to improve their health was motivated by their relationship with their family. During difficult times, community members felt that they could count on their family and/or the community to come together for any type of support.

But I really thought about my health over the last three or four years because what they told me at the time, too, was that if you don't do the surgery, you won't be here in five years. So that's another two years away. And I said, I want to live long. I got eight grandchildren and

Wali et al. Strategies to Support First Nations Heart Health

> one great grandson. So, I've since kind of watched myself a little bit better and, you know, hopefully continue to keep doing that. (Community Member 1)

> I had experience with a nine-year-old boy that drowned on the river... for three days he was trying to get the body and the spirit of Moosonee and Moose Factory was fantastic. They had people on with (sic) the boat, walking in. I couldn't believe like how everybody got together. (Community Member 5)

Valuing the strength of meaningful relationships, many community members felt clinicians did not understand who they were as an individual, but instead focused on the core metrics associated with their condition. With the number of temporary locums across the JHB communities, HCPs failed to understand the impact of a patient's personal life and living conditions on their health status. Among these factors, the influence of family dynamics was especially evident for women in the community, as gender roles led women to vocalize their health issues less, as family responsibilities often were given higher precedence than the severity of their symptoms.

We don't have personal doctors we see every day or every second day, you know, we see doctors coming for a couple of weeks or one week and they're gone again . . . locums, you know, we experience that every day . . . and one of the things that I experience over at the hospital is like, if I'm going into something that I feel is not normal, a young doctor comes to see me, he says I checked your chart for two years, and he says your blood pressure has been going up and down. I said, yeah, well, I don't take medication. I don't want to take medication for my blood pressure. It goes up and down, yes. But what he failed to ask me is what's been going on with you for the last two years? He didn't ask me those questions. He doesn't know that my son is in a mental health facility with schizophrenia for the last 10 years. He doesn't know that. He doesn't know that my wife had two heart surgeries, two spinal surgeries, and I'm taking care of her for the last twenty-five years. So, I'm thinking the doctors should be aware of that. They should ask me ok, what's been happened (sic)? (Community Member 2)

So, I've been retired for about 11 years, maybe 11 years, and I'm raising one of my great grandchildren, for two years now they've been with me. And so, and family is very important and that was my issue. (Community Member 1)

With the relatively weak patient-clinician relationships, community members indicated that they were often hesitant to describe the details of their condition or ask for further care support. Given the history of poor clinical experiences and the presence of clinician power dynamics, the concept of "white coat syndrome", whereby a patient feels anxious in a medical environment or presence of a clinician, was also recognized as a common barrier. To rebuild the community's trust with the healthcare system, clinicians need to work on strengthening their relationship with patients, by first understanding who they are as individuals.

There is an issue with white coat syndrome. I have a friend that when she goes to hospital or doctor even, he doesn't wear a white coat, but it's still the fact that he's going, she's going to the doctor. She gets stressed out, her blood pressure rises, and she gets all flustered because she's nervous. And that raises the blood pressure as well. (Community Member 4)

Theme 4: innovative solutions start with community

Recognizing the community's desire to improve their health within the limitations of their contextual

environment, many community members felt that in order for them to be able to take back control of their health, new modes of healing would need to be introduced. One community member shared his journey of using an Apple Watch to monitor their physical activity level, and said that after 3 years of consistent use, he was able to lose over 55 lb. By working on taking small steps to improve the aspects of their health that were in their control, community members were able to work toward improving their heart health as a whole.

Sometimes we get stuck in somebody else's definitions or theories or whatever... Our hearts, we got to start looking for ways, how we get more healthy. You know, we live in this community, but sometimes we just don't know what's out there, what's better out there in terms of medicine and so on and so forth. (Community Member 8)

I got an Apple Watch walking and there's just the walking and you know, the walking has really helped me, and I feel great like I was a big person at one time. I think I was about 240 pounds. I'm now down to about 185. So, and with a lot of walking, this is over the last three years, and I really watched myself for a while for health, health wise watching what I ate, and they said it's normal to kind of have something sweet once in a while. (Community Member 7)

With the positive experiences associated with digital care solutions (ie, Apple Watch), various community members became more open to the use of technology to support their heart health. Some community members shared their concerns regarding digital care solutions and some of the core requirements a tool would need to motivate their sustained use of it. Specifically, the use of customized notifications and automized self-care steps were recognized as core components needed to prevent the tool from being burdensome. Given that many older adults in the community spoke Cree or had difficulties hearing, offering the tool in multiple languages was fundamental to ensuring its adoption.

I was just going to add on like for what she said like the whole notification would drive you crazy. And that's notification as well. But if they have an option where you can turn off some of the notification and turn it on when you want to use it, would that be a good option. (Community Member 4)

It's really hard for Elders who have hard of hearing or are Creespeaking and need translators. It really slows down their visit. And also, the internet is poor here right now. It's finicky. So those are some challenges. I just wanted to add on a telemedicine part. (Community Member 6)

Aside from concern about the technical requirements of the tool was concern regarding whether individuals would be able to learn how to use its functions. As revealed by the discussions among community members, many felt that by implementing a community-based education workshop, individuals of varying technological literacy levels would be able to learn how to use the device. Another concern highlighted by community members involved the fear of technology-based solutions replacing in-person care. To provide a sense of security and confidence in the use of innovative care solutions, working in partnership with communities to understand their local needs was recognized as important by one community. Through an understanding of the history of the local environment and the values of the community, this approach would lead to the implementation of more compassionate and trusted care tools.

What about a session? Get a group like this and you learn how to use it. You can have a watch, but if you can't use it, you don't know how to use it. But if you have five, three, four people that gathers and tells you (sic), ok, this is what you have to do, that makes a big difference too. (Community Member 5)

But I think what a lot of people worry about is that it's going to replace the one-on-one treatment that you will get with a doctor. But I think there is a population here, where devices that they can use, and wear would be beneficial... But yet what I think things like this [sharing circle] are very good for is it just shows your respect for the area coming your into (sic) and trying to do something like this, and you want to interact with the people. And I think it just helps build trust with community and you guys in Toronto trying to bring a service here. Because there is a lot of mistrust in the medical field. (Community Member 4)

Despite the benefits that a context-specific digital tool could provide for heart healthcare, community members felt that innovative care strategies also should look to acknowledge and understand the benefits of Indigenous ways of healing. With Western biomedicine often overpowering Indigenous sources of wellness, integrating herbal remedies and traditional diets alongside clinical guidelines was recognized as pivotal. In Moosonee, a local dietitian currently provides culturally informed guidance on heart healthy diets within the context of various traditional foods. Thus, to empower heart health management, care solutions should seek to integrate aspects of Indigenous culture, tradition, and community, within the design and delivery of a care solution.

I was very, very sick at home, so I thought, oh, I'll get better, I'll feel better tomorrow. So, I'm okay here as long as I drink my Indian tea, lavender tea. So, it helped me a little bit to manage the whole night alone. (Community Member 2)

Yes, so we do have a dietician. We specifically try to provide guidance around heart healthy foods and really, it's about a balanced diet, is what is we're looking for. So, trying to ensure looking at your portion control, balancing out your carbs, your carbohydrates, or your starches, or your Bannock [Indigenous food] with your fruits and vegetables and with some source of protein. (HCP 2)

Discussion

Principal findings

With the presence of various colonial constructs within the current healthcare system, First Nations communities continue to experience a disproportionate burden of CVDrelated risk, compared to the general population. Despite the fact that many studies and government agencies have recognized the consequences of First Nations communities having faced years of adversity, the communities are provided with limited support and resources to improve their community conditions. With a range of obstacles from the lack of clinical expertise available to the unaffordable costs of basic foods, First Nations communities are left with minimal opportunity to support their health and well-being. 5,17 Given that current healthcare services fail to integrate Indigenous health paradigms within the delivery of Western biomedicine, heart health strategies are needed to broaden care support through the lens of multiple worldviews. To address this aim, this study worked in partnership with the Moosonee

community to better understand the requirements for a heart health strategy that is reflective of the local community's needs, priorities, and capabilities.

By using a community-based approach, centred on the values and traditions of the Moosonee community, participants were able to openly discuss the various challenges they experienced when accessing cardiac care support. The various stories shared revealed that many community members experienced a discontinuous journey for their care management, as the lack of clinical resources often resulted in delaying a patient's diagnosis. With the limited clinical investigation available, patients felt that the burden of travel outweighed the benefit of clinical support. This perspective has been shared by many Indigenous communities across Canada, as the inequitable distribution of healthcare resources has led individuals to no longer see the value of clinical support. In many cases, Indigenous people felt that the opportunities for care continuity would be limited, as specialist interactions were significantly rare.^{5,34} Instead, to better incentivize and empower health management, bringing sources of care closer to home were recognized as pivotal features for a successful heart health strategy. In the sharing of this idea, the use of innovative solutions, such as digital tools, was discussed in relation to its ability to reduce barriers associated with travel and care continuity. Given the supportive feedback from local community members regarding use of the Apple Watch, digital tools were viewed as valuable supports, as long as they remained simple to use and customizable for patient preferences. Specifically, with the varying technology literacy among community members, training is needed before the benefits of digital tools can be realized. In Fontaine et al., a group of First Nations women developed an educational program for heart health and nutrition, by creating a series of digital stories describing how to live with the challenges of their heart condition in relation to their current culture and lifestyle. 19 By leveraging a similar approach, our teams can work in collaboration with the local community to codevelop a workshop focused on educating community members on digital tool use and the core aspects of better care for their heart. This workshop will serve as a resource to empower community members to utilize more innovative solutions for

A key issue recognized by community members was the level of mistrust of the healthcare system. Given the limited time that locum clinicians spent with patients, they were unable to understand the complexity of an individual's wellbeing, apart from their clinical metrics, and in turn, community members did not see the value of their clinical interactions. Recent reports have attributed the low use of primary care services amongst First Nations people to the negative experiences they have faced during clinic visits.³ Given that many individuals often turn to the emergency department or medical evacuations as the last resort for care support, the need is apparent for clinicians to establish meaningful patient-clinician relationships, to begin destigmatizing clinical care.³⁵ With the history of abandonment and exploitation of First Nations populations, community members have relied on their family and the community as their only sources of support. A shared history of resilience has led community members to feel a sense of responsibility to support one another during times of difficulty. Given this, to

Wali et al. Strategies to Support First Nations Heart Health

move toward a heart health strategy centred on trust and community values, clinicians need to dedicate significant efforts to strengthening their current patient relationships, as well as integrating aspects of traditional knowledge within the delivery of clinical care. To facilitate achievement of this aim, previous studies have embraced different Indigenous cultural practices (ie, storytelling, sharing circle, blanket ceremony) to allow clinicians to speak from a space of vulnerability that promoted mutual learning.³⁶ By using this approach, in Ziabakhsh et al., a team of Indigenous women and non-Indigenous nurse practitioners were able to collaboratively transform a heart health education program from a 10-minute clinical discussion into a 50-minute session exploring topics related to both Western and Indigenous practices for heart health (eg, smoking cessation education, tobacco use for ceremonial purposes). Our team aims to integrate the teachings from Ziabakhsh et al. in our follow-up sharing circles, to facilitate a discussion on how the strengths of Indigenous practices can be integrated within proposed heart health strategies and the design of digital tools.

Limitations and future research

This study has a number of limitations. First, recruitment efforts were designed to invite community members from varying age groups and genders; however, mostly older women were involved in the study. Second, community voices represented in the study findings were limited, as only 6 community members, with one or more heart conditions, participated in the sharing circle. Given that recruitment was based on the willingness and availability of community members to participate, we recognize that these limitations may have arisen due to selection bias within the study. As part of the continued partnership efforts, we aim to work with the local team to integrate a greater level of community outreach for the next sharing circle. Third, despite inviting community members to participate in the data-analysis stage of the study, only one individual provided input for this. Community members also did not review the quotes used within the article, which may have resulted in the narrative being construed within the study themes. Fourth, although this study was hosted in the town of Moosonee, a few community members residing in Moose Factory attended the sharing circle, as they felt that the 2 communities faced similar care challenges. Given the relative differences between the Moosonee and Moose Factory contexts, some biases may be present in the data. To mitigate this challenge, this project has continued its engagement efforts to obtain approval for community-based sharing circles across the various JHB communities. By collaboratively reviewing the contextual differences within each community's heart health priorities, this study aims to highlight the importance of understanding the uniqueness of each community's needs. The goal of this research is to build on the findings from the initial sharing circle, hosted in Moosonee, to better understand the dynamics of each community and the values that would be integral for the development of a community-first heart health strategy. Given that predeveloped care programs often have minimal benefit for the local community, through this partnership, our teams envision that a series of follow-up sharing circles will be held, whereby community members

can provide direct input on the proposed design and delivery of a heart health program.

Conclusion

Across Canada, many Indigenous communities experience worsening health outcomes due to the systemic conditions that have limited their ability to manage their health and wellbeing. With many interdependent factors contributing to Indigenous health inequities, this study worked in partnership with the Moosonee community to better understand their local needs and priorities for heart health and wellness. Given the remoteness of the Moosonee community, several factors related to limited care resources and the burden of travel resulted in discouraging community members from seeking care support. Given the importance of meaningful relationships, the community's current mistrust of the healthcare system left many individuals to turn to family and community for reliable support. Although technological aids were used only minimally for care management, the community valued their functionality in bringing care closer to home. Given this context, innovative strategies, such as digital tools, can be leveraged to support heart health and wellness in the community, but the design of these strategies needs to integrate both Western and Indigenous approaches to healing.

Acknowledgements

The authors recognize the guidance provided by Elder Greg Spence and the Weeneebayko Area Health Authority. The authors also thank the Moosonee community for sharing their stories and lived experiences throughout this study.

Ethics Statement

This study was approved by the Weeneebayko Area Health Authority's Research Ethics Committee. The town of Moosonee's Mayor's office was also informed of all study activities.

Patient Consent

The authors confirm that patient consent forms have been obtained for this article.

Funding Sources

This study was supported by the Ted Rogers Centre for Heart Research.

Disclosures

The authors have no conflicts of interest to disclose.

References

- Vervoort D, Kimmaliardjuk DM, Ross HJ, et al. Access to cardiovascular care for indigenous peoples in Canada: a rapid review. CJC Open 2022;4: 782-91.
- Smylie J, O'Brien K, Xavier CG, et al. Primary care intervention to address cardiovascular disease medication health literacy among indigenous peoples: Canadian results of a pre-post-design study. Can J Public Health 2018;109:117-27.

- Institute for Health Metrics and Evaluation. Global burden of disease results tool. Available at: http://ghdx.healthdata.org/gbd-results-tool%20. Accessed October 25, 2021.
- Statistics Canada. Table 13-10-0394-01 Leading causes of death, total population, by age group. 2022. Available at: https://www150.statcan.gc. ca/t1/tbl1/en/tv.action?pid=1310039401. Accessed July 15, 2022.
- Reading J. Confronting the growing crisis of cardiovascular disease and heart health among Aboriginal Peoples in Canada. Can J Cardiol 2015;31:1077-80.
- Atzema CL, Khan S, Lu H, et al. Cardiovascular disease rates, outcomes, and quality of care in Ontario Métis: a population-based cohort study. PLoS One 2015;10:e0121779.
- Trevethan S. Strengthening the availability of First Nations data. Available at: https://www.researchgate.net/publication/332543405_Trevethan-2019-Strengthening_the_Avail_of_FN_Data_e. Accessed July 16, 2022.
- Young TK. Cardiovascular health among Canada's Aboriginal populations: a review. Heart Lung Circ 2012;21:618-22.
- First Nations Information Governance Centre (FNIGC). First Nations regional health survey (RHS) phase 2 (2008/10): national report on adults, youth and children living in First Nations communities. Ottawa: FNIGC, 2012. Available at: https://fnigc.ca/wp-content/uploads/2020/ 09/8b5dee11df2a6370ac3bce7c41ab6704_first_nations_regional_health_ survey_rhs_2008-10_-_national_report_child_2.pdf. Accessed July 16, 2022
- Smylie J, Firestone M, Spiller MW. Tungasuvvingat Inuit. Our health counts: population-based measures of urban Inuit health determinants, health status, and health care access. Can J Public Health 2018;109: 662-70
- Heart and Stroke. A holistic approach to Indigenous health. Available at: https://www.heartandstroke.ca/articles/a-holistic-approach-to-indigenous-health. Accessed July 18, 2022.
- 12. Huffman MD, Galloway JM. Cardiovascular health in Indigenous communities: successful programs. Heart Lung Circ 2010;19:351-60.
- 13. Allen L, Hatala A, Ijaz S, Courchene ED, Bushie EB. Indigenous-led health care partnerships in Canada. CMAJ 2020;192:E208-16.
- Adelson N. The embodiment of inequity: health disparities in Aboriginal Canada. Can J Public Health 2005;96(Suppl 2):S45-61.
- Bird-Naytowhow K, Hatala AR, Pearl T, Judge A, Sjoblom E. Ceremonies of relationship: engaging urban indigenous youth in community-based research. Int J Qual Meth 2017;16:1609406917707899.
- Truth and Reconciliation Commission of Canada. Calls to action. Available at: https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf. Accessed July 17, 2022.
- Anand SS, Abonyi S, Arbour L, et al. Explaining the variability in cardiovascular risk factors among First Nations communities in Canada: a population-based study. Lancet Planet Health 2019;3:e511-20.
- Hammond C, Thomas R, Rice C. Widening the circle of care: digital stories of community-based caregiving in a Mohawk First Nation. Int J Indigen Health 2022;17:82-95.
- Fontaine LS, Wood S, Forbes L, Schultz AS. Listening to First Nations women'expressions of heart health: mite achimowin digital storytelling study. Int J Circumpolar Health 2019;78:1630233.
- Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. Am J Public Health 2010;100:S40-6.

- Frerichs L, Lich KH, Dave G, Corbie-Smith G. Integrating systems science and community-based participatory research to achieve health equity. Am J Public Health 2016;106:215-22.
- Prodan-Bhalla N, Middagh D, Jinkerson-Brass S, et al. Embracing our "otherness" a mutually transformative journey in delivering an indigenous heart health promotion project. J Holistic Nurs 2017;35:44-52.
- Weeneebayko Area Health Authority. Mission, vision, values. Available at: https://www.waha.ca/mission. Accessed July 19, 2022.
- Donio PJ, Freitas C, Austin PC, et al. Comparison of readmission and death among patients with cardiac disease in northern vs southern Ontario. Can J Cardiol 2019;35:341-51.
- White E. After a decade of delays, there's now debate on where James Bay hospital should be built. Available at: https://www.cbc.ca/news/canada/ sudbury/james-bay-moose-factory-moosonee-hospital-future-1.5356135. Accessed July 19, 2022.
- Herbert CP. "Nothing about us without us": taking action on indigenous health. Open Letters from Canadian Leaders in Healthcare series. Available at: https://www.longwoods.com/content/24947/insights/nothing-about-us-without-ustaking-action-on-indigenous-health. Accessed July 19, 2022.
- Macdonald NE, Stanwick R, Lynk A. Canada's shameful history of nutrition research on residential school children: the need for strong medical ethics in Aboriginal health research. Paediatr Child Health 2014;19:64.
- 28. Wali S, Superina S, Mashford-Pringle A, Ross H, Cafazzo JA. What do you mean by engagement?—evaluating the use of community engagement in the design and implementation of chronic disease-based interventions for indigenous populations—scoping review. Int J Equity Health 2021;20:8.
- Geia LK, Hayes B, Usher K. Yarning/Aboriginal storytelling: towards an understanding of an indigenous perspective and its implications for research practice. Contemp Nurse 2013;46:13-7.
- Government of Canada Panel on Research Ethics. Tri-Council policy statement 2—chapter 9: research involving the First Nations, Inuit and Métis Peoples of Canada. Available at: https://ethics.gc.ca/eng/tcps2eptc2_2018_chapter9-chapitre9.html. Accessed July 18, 2022.
- 31. Maar M, Yeates K, Barron M, et al. I-RREACH: an engagement and assessment tool for improving implementation readiness of researchers, organizations and communities in complex interventions. Implement Sci 2015;10:64.
- Peltier C. An application of two-eyed seeing: indigenous research methods with participatory action research. Int J Qual Meth 2018;17: 1609406918812346.
- Eakin JM, Gladstone B. Value-adding" analysis: doing more with qualitative data. Int J Qual Meth 2020;19:1609406920949333.
- 34. Gordon J, Kirlew M, Schreiber Y, et al. Acute rheumatic fever in First Nations communities in northwestern Ontario: social determinants of health "bite the heart.". Can Fam Phys 2015;61:881-6.
- First Nations Health Authority. First Nations health status and health services utilization: summary of key findings 2008/09-2014/15. Available at: https://www.fnha.ca/WellnessSite/WellnessDocuments/FNHA-First-Nations-Health-Status-and-Health-Services-Utilization.pdf. Accessed July 18, 2022.
- Ziabakhsh S, Pederson A, Prodan-Bhalla N, Middagh D, Jinkerson-Brass S. Women-centered and culturally responsive heart health promotion among indigenous women in Canada. Health Promot Pract 2016;17:814-26.