

“Because you love us as much as we love you”: The role of community relationships in facilitating Indigenous engagement in healthcare

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“Because you love us as much as we love you”: The role of community relationships in facilitating Indigenous engagement in healthcare

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ABSTRACT

Grounded in relational worldviews and ways of being, Indigenous health on Turtle Island once thrived. However, colonization disrupted and sought to delegitimize Indigenous relationships, having devastating impacts on Indigenous health and contributing to persistent Indigenous health disparities. Making matters worse, Indigenous Peoples face barriers to engagement in mainstream Canadian healthcare, including racism and the marginalization of Indigenous relational conceptions of health and ways of caring. Using an Indigenous methodology, we explored Kanyen'kehá:ka (Mohawk) relationality between community members and community-based healthcare providers (n = 25), and how these ways of relating shaped engagement in community-based care. Our analysis identified three key themes: in Kenhté:ke (Tyendinaga) the concept of health goes beyond western definition and is broadly defined and relational; connectedness and shared experiences are foundational to Kenhté:ke identity and ways of caring; and relationships that reflect community connection foster more engagement in healthcare than otherwise in western care settings. These findings have critical implications for western norms of healthcare professional training and practice and the need to include Indigenous relational ways of caring and conceptions of health.

1. Positionality

Jodi is Kanyen'kehá:ka (Mohawk), Bear clan and was born and raised in Kenhté:ke (Tyendinaga) where she still lives with her family and has been working as an allied healthcare professional. Jodi learned many lessons supporting community members on their health journey about the power of relationships and both individual and community strength. Its those lessons that inspired this work.

Heather is white, with ancestry from the UK. She was born in the territory of the Yellowknives Dene. She now lives and works in the traditional territories of the lək'wəŋən speaking peoples of the Esquimalt and the Songhees Nations – and the SENĆOŦEN speaking peoples of the W̱SÁNEĆ First Nations. Her research program concentrates on upholding Indigenous Peoples' self-identified priorities using strengths-based approaches.

Jodi and Heather share a heartfelt commitment to Indigenous health. Our aim in this paper is to contribute Kanyen'kehá:ka voice, values and desires to the spaces of healthcare, shift deficit narratives, and illuminate the transformative power and potential of Indigenous professionals

caring for Indigenous Peoples rooted in community connection, values, and ways of being.

2. Introduction

Like many Indigenous nations, the Kanyen'kehá:ka are relational people (Hill, 2015; Hovey et al., 2014; Porter, 2008). These relational ways of being encompass interconnecting human relationships between the individual, family, community, and the environment grounded in responsibility, humility, reciprocity and respect (Akwasasne Notes, 2005; Hovey et al., 2014; Nelson, 2008). Within this relational worldview and way of being, Indigenous Peoples once thrived (Richmond, 2017). They had health-protecting and health-promoting lifestyles, protocols, and practices that supported their overall good health.

White supremacist ideologies and colonial policies have intentionally disrupted these Indigenous values and relationships and have sought to delegitimize relational ways of being (Castleden et al., 2016; Greenwood et al., 2018; Waldram et al., 2006) which has had devastating impacts on Indigenous life and health (Akwasasne Notes, 2005;

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Cortassel, 2012; Castleden et al., 2016). Today in Canada, Indigenous Peoples have lower life expectancy than the general Canadian population and higher rates and worse outcomes of chronic disease such as diabetes, cardiovascular disease, and cancer (PHAC, 2016; Cancer Care Ontario, 2017). By definition, chronic disease is a long-term condition in which sustained healthcare engagement is ideal for optimizing management and health outcomes (Davy et al., 2017). However Indigenous Peoples face barriers to engagement in mainstream Canadian healthcare such as racism and marginalization, at multiple levels. These barriers contribute to rather than ameliorate health disparities (Allan and Smylie, 2015; Nguyen et al., 2020; Reading and Wien, 2009).

Indigenous and allied health scholars argue that Indigenous conceptions of, and approaches to, health and healing are required to better understand and support Indigenous health and engagement in healthcare, including relational approaches to health, healthcare and health research (Greenwood and Lindsay, 2019; Kennedy et al., 2022). From a strengths-based approach (Kennedy et al., 2022; Syliboy and Hovey, 2020), the overarching goal of the research reported on in this article is to contribute to emerging literature on Indigenous healthcare provided by Indigenous Peoples in their own communities and on facilitators of Indigenous engagement in healthcare more generally. Members of Mohawks of the Bay of Quinte living within the community of Kenhté:ke who access allied health and nursing care from community members participated in this research to explore Kanyen'kehá:ka relational ethics, how these ways of relating may differ from typical western healthcare interactions, shape healthcare relationships and impact engagement in care.

3. Background

Anti-Indigenous racism and white supremacy is woven into the fabric of Canadian society, including its institutions, contributing to health disparities across domains of Indigenous life (Allan and Smylie, 2015; Browne et al., 2016; Castleden et al., 2016; Banerjee and Tan, 2022; Jongbloed et al., 2023). The Canadian healthcare system is no exception and has repeatedly been defined as unsafe by Indigenous Peoples across the country (Brooks-Cleator et al., 2018; Browne et al., 2016; Crowshoe et al., 2019), resulting in fear, mistrust, discomfort, disengagement, and care avoidance (Crowshoe et al., 2019; Horrill et al., 2018; Jacklin et al., 2017). These racist and marginalizing healthcare interactions are structural, systemic, and pervasive for Indigenous Peoples impacting individuals and communities alike (Allan and Smylie, 2015; CAHS, 2023). Despite attempts within the sector to create culturally safe and equitable care (Browne et al., 2016; Castleden et al., 2010; Brooks-Cleator et al., 2018), racism and marginalization of Indigenous values, conceptions of health and ways of caring persist, impacting interpersonal interactions with healthcare providers (Allan and Smylie, 2015; CAHS, 2023; Walker and Behn-Smith, 2018).

The professionalization of Canadian healthcare education, training, and provision is founded on the biomedical model of care which works to shape the beliefs, attitudes, and actions of care providers. This model considers health as a simple absence of disease at the individual biological level and provides minimal insight into the cultural, social, political, historical, and environmental factors influencing health (Horrill et al., 2018). By 1948, the World Health Organization had advanced a broader definition of health as, "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO Interim Commission, 1948, p. 100 as cited in Larsen, 2022). But for many Indigenous Peoples conceptions of health extends even further to include a more wholistic and expansive spectrum of factors including the significance and centrality of connection and relationships to health (CAHS, 2023; Eni et al., 2021; Hovey et al., 2014; Kennedy et al., 2022). As such mainstream healthcare interactions are often at odds with Indigenous individuals' and communities' values, conceptions of health and ways of caring (Allen et al., 2020; Walker and Behn-Smith, 2018; Nelson and Wilson, 2018).

In Canada, for example, the Canadian Medical Association's Code of Ethics and Professionalism states: "Limit treatment of yourself, your immediate family, or anyone with whom you have a similarly close relationship to minor or emergency interventions and only when another physician is not readily available" (CMA, 2018). This and other health professions' codes of conduct emphasize the importance of objectivity, the risk of compromised professional integrity if emotional or personal affiliation is present, and the threat of hindered judgement during assessment (Canadian Medical Protective Association, 2022; College of Dietitians of Ontario, 2017).

Yet, evidence suggests that centering close relationships has the potential to mitigate past harms, create trust, and foster Indigenous engagement in healthcare (Jacklin et al., 2017; Crowshoe et al., 2019; Walker and Behn-Smith, 2018; Lin et al., 2023). Engagement or active involvement in healthcare includes open and honest communication with healthcare providers, such as asking questions and disclosure of health behaviours and symptoms, as well as returning for follow up appointments, optimizing health outcomes (Bourque Bearskin et al., 2024). However, healthcare providers in mainstream settings have been found largely unable to recognize interpersonal differences in cultural values and ways of caring and continue to lack the knowledge and values necessary to facilitate trusting relationships and Indigenous engagement in care (Browne et al., 2016; Nguyen et al., 2020; Stevenson and Tobias, 2022). Further, professional practice standards, which guide regulated healthcare professional practice by establishing the norms for safe, professional and ethical care provision (Ontario Ministry of Health, 2024) are driven by biomedical notions and likewise largely devalue the importance of honouring and fostering meaningful relationships of care and constrain Indigenous relational ways of being (Greenwood and Lindsay, 2019; Walker and Behn-Smith, 2018).

Alternatively, research demonstrates that the presence of Indigenous healthcare providers increases a sense of safety and belonging among Indigenous clients (Davy et al., 2016; Nelson and Wilson, 2019). Moreover, Indigenous and allied health scholars assert that healthcare that is informed by, and grounded in local cultural conceptions of health, values and ways of caring are more effective and likely to bring about health improvements in Indigenous populations (Allen et al., 2020; Brooks-Cleator et al., 2018; Kennedy et al., 2022; Richmond and Cook, 2016). Australian literature, for example, on the impacts of Indigenous community healthcare suggests that Indigenous staff, whether it be clinical or administrative were more likely to build stronger relationships with clients and that Indigenous community care is more likely to be free of racism, congruent with local health beliefs and tend to employ Indigenous staff who are known by those seeking care (Davy et al., 2016). All of which were found to facilitate engagement in care (Davy et al., 2016).

However, there remains scant literature in the Canadian context (and globally) of Indigenous Peoples' perspectives of receiving community-based care from community members (Allen et al., 2020). To date, most studies of Indigenous experiences in healthcare settings center care provider perspectives (Harding et al., 2021) or report on care received mainly by non-Indigenous care providers in various settings and there remains very little research by Indigenous researchers into Indigenous care provided by their own people in their own communities (CAHS, 2023). From a community-engaged, strengths-based view (Kennedy et al., 2022; Syliboy and Hovey, 2020), our intent is to contribute to the limited literature on Indigenous healthcare provided by Indigenous professionals in their own communities and on facilitators of Indigenous engagement in care more generally.

The central question we explored was: What Kanyen'kehá:ka values and ways of being are present in building relationships with healthcare providers when both provider and client are Kanyen'kehá:ka community members from the same territory? The purpose of our study was to explore Kanyen'kehá:ka relational ethics, how these ways of relating may differ from conventional western clinical healthcare interactions, how they shape healthcare relationships, and how they influence

willingness to engage in healthcare.

4. Methodology & methods

Using Indigenous methodologies (Kovach, 2010; Smith, 1999; Wilson, 2008) inspired by the Ohén:ton Karihwatéhkwén (Haudenosaunee Thanksgiving Address) these questions were explored with adult registered members of the Mohawks of the Bay of Quinte living within the community of Kenhté:ke who access allied health and nursing care from community members at the Community Wellbeing Centre, located in the community. The Ohén:ton Karihwatéhkwén centers connection of all things which reminded that our research actions have impact. It likewise centers gratitude which reminded us to be thankful for the gifts of time and knowledge that were shared, and of our responsibility to handle these gifts with great care and to continue to uphold and foster community relationships throughout the research process, and beyond. In practical terms this meant using processes and methods that were congruent with these values.

For Jodi, as a community member who continues to live, work, and raise a family in the community, strong reciprocal relationships and a sense of responsibility were already present, ongoing, and personally valued outside of the research. To ensure community support for the study, the community's leaders and community members alike were approached regarding the utility and relevance of this project to community. Advice and input from a respected community Elder was also sought to ensure grounding in Kanyen'kehá:ka worldview. In accordance with Article 9.3 of Canada's Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research et al., 2018), a Mohawk Band Council Resolution of Support was also received on April 5, 2022 and Queen's University gave ethical clearance shortly thereafter (September 7, 2022).

A community advisory committee was assembled during initial planning to ensure community input at all stages of the research, increase community voice, and share decision making power (Windchief and San Pedro, 2019). The committee met approximately every three months and more frequently when needed. Recruitment was done informally by Jodi based on pre-existing relationships using community connections with former clientele. Potential participants were contacted by phone, email, during unrelated online community health events, and by chance encounters in the community.

In keeping community relationships central, the project employed relational methods of data collection as described by Kovach (2010) and Windchief and San Pedro (2019), including visiting and a research roundtable. Haudenosaunee scholar Thomas (2013) defines visiting as the community-based process of building and maintaining meaningful relationships. Most one-on-one visits were held virtually in consideration of the COVID-19 pandemic. However, some visits and the research roundtable were held in person as per participant request and during the period when all restrictions on social gatherings had been lifted. Most visits were approximately 1 h, while the research roundtable was 2 h. Data were collected in 2022 and 2023.

The research roundtable was unplanned and sprung to life organically during an unrelated community event. It was different from a researcher-led focus group in that it was named, developed, and planned by a community member who supported the work, rather than Jodi. In essence it was similar to an Indigenous sharing circle in structure and sense in that it was a fluid, conversational style group meant to provide space and time for participants to share their stories as directed by them (Lavalee, 2009; Tachine et al., 2016). Likewise, the research roundtable was rooted in community relationships, the facilitators also engaged in sharing as active participants and the group practiced listening, each allowing the others the time they needed to share their perspectives and building off of each other (Lavalee, 2009; Tachine et al., 2016). Food and beverages were also enjoyed during the event. The research roundtable differed from a typical sharing circle in that participants were free to speak as they wished, rather than moving in a specific

direction around a circle. Unlike a focus group though, Jodi was primarily there to respectfully receive and respond to participants' perspectives, not guide the discussion.

One-on-one visits and the research roundtable were audio recorded and transcribed by Jodi. All participants of one-on-one interviews were offered a copy of their transcript for their review and approval prior to thematic analysis. Due to the synergistic nature of the research roundtable, participants were not offered the opportunity to make changes to the transcript. However, an appreciation event that included lunch was held during the research team's initial thematic analysis, which also permitted the opportunity to share initial interpretations and allow opportunity for further input and feedback. What we heard there was confirmation of our analysis.

A combined approach to data analysis was taken using both interpretive meaning making (Kovach, 2000) and thematic analysis to identify themes, concepts, and patterns of meaning (Chilisa, 2020; Creswell and Poth, 2018; Hay, 2016). Several close readings of the transcripts and reflexive notes created the space to identify and refine themes and reflect on meaning. A combination of descriptive and analytic codes were also inductively developed based on reoccurring themes. Transcripts were then coded and analyzed thematically using NVivo 12.0 Plus (QSR International, 2018).

Emergent themes and findings were shared with the community advisory committee for review and feedback. All participants received a document that showed how their individual quotes were used in the context of the analysis to allow them the opportunity to request changes to, or to reject the use of, their contribution in public outputs. No one withdrew their consent. Finally, upon completion of this article, participants had a last chance to review their contribution to ensure continued consent (Canadian Institutes of Health Research et al., 2018; TCPS2 article 3.3) and comfort with how their perspectives were being expressed.

In total, 25 community members shared their experiences of receiving allied health and nursing care in Kenhté:ke. One participant was non-Indigenous but has lived in the community for over 45 years and attends appointments with their Kanyen'kehá:ka spouse regularly. Seventeen participants had one-on-one visits while 12 attended the research roundtable. Four participated in both forms of data collection. Four participants identified as men, one as a trans person, and twenty as women. The gender representation of participants generally reflects that of the population engaging in community-based care; that is, there are a greater number of adult women accessing care than other groups. Thus, it was not a surprise that more women participated in this study. At the same time, efforts were made to include men and gender non-conforming groups in recruitment and data collection, but ultimately the majority of participants identified as women. Gender was likewise considered during data analysis, however no significant differences across gender lines were formed.

The age range was between 36 and 89 years old. Though not targeted specifically, nine participants were also community care providers in various health and social services, thus offering insights both as receiver and provider of community care with Kenhtekehró:non (Mohawk people who live in Kenhté:ke).

5. Findings

Our analysis reveals that healthcare relationships between community members were grounded in wholistic and relational conceptions of health and healthcare, shared identity, and community connection, which facilitated sustained engagement in care, and for some, motivated self-care beyond the healthcare setting. When comparing community healthcare with their typical experience of western care interactions, participants noted that community members; were more apt to approach care provision relationally and collaboratively; and to spend more time with them laughing and relating from a place of connection, warmth and even love, building closer interpersonal relationships of care. These

relationships were described as fostering mutual understanding and acceptance, trust, comfort, support, and as decreasing feelings of judgement and vulnerability. Conversely western care interactions were typified as cold, clinical, distant, and uncaring.

These findings were grouped into three broad themes: (1) For Kenhtekehró:non, health is broadly defined, wholistic, and relational; (2) A sense of connection is foundational to Kenhté:ke identity and ways of caring, and (3) Relationships and connection foster engagement in care. Participants frequently spoke about relationships, health, and community interchangeably illuminating their inherent relatedness. Participants likewise blurred the lines when speaking about community connection, relationships, and identity or how they identify as Kenhtekehró:non, again alluding to the interconnection of these concepts. Thus, while not mutually exclusive, these findings are teased apart here for readability. Direct participant quotes are used to showcase themes. To protect identities participants were assigned numbers.

5.1. Theme 1: Health is broadly defined, wholistic, and relational

“Your family, your relations, everything that is about you, is what makes your health.” - P13

When defining health participants certainly talked about physical health such as presence or absence of disease and pain. Many made mention of physical factors such as weight, blood pressure, blood sugar and how they take care of their physical bodies, which resonates with western biomedical notions of health. However, most also moved beyond physical parameters to a more expansive definition that also included factors such as balance and the connection of all things as being integral to health.

“Health means balancing all these various boiling pots we have on our stove of life. Whether it’s physical, medical, mental, emotional, it’s all conducive to the one. Each one impacts the other”

- P01

Mental health, emotions, and one’s mindset was also described by several as being central to health. Gratitude as well as happiness, enjoyment, and acceptance emerged as central values and feelings related to what it means to be in good health and taking stock of whether one is healthy.

“I’d say have a check up when you’re supposed to every year. Eat well, exercise, have good mental attitude and be good to all mankind and be really grateful that you’re alive and enjoying life.” - P20

“You feel good, you generally wake up in the morning, are glad to be alive and you don’t have any aches and pains.” - P09

Many likewise related relationships and social supports as being central to their health. Several made mention of the impacts we have on each other, and the importance of family and community to their health.

“When you talk about what it means to be healthy, I ask am I happy? Am I able to do the things that I want to do? Am I still part of my community? And am I being a good mom?” - P03

The ways in which most participants conceptualized health resonates with the Ohén:ton Karihwatéhkwén in terms of core values and ways of being that prioritize relationships, gratitude and connectedness (Akwasasne Notes, 2005; Porter, 2008). Some further acknowledged that their view of health did not connect with mainstream healthcare perspectives contributing to negative and marginalizing experiences.

“When I went to see the other lady [outside community] I lost weight, but I was very unhappy. I was skinnier, but I was not happy. And that didn’t make me feel healthy” - P03

5.2. Theme 2: Connection is foundational to Kenhté:ke identity and ways of caring

“In community there is a we as opposed to a you” - P01

Connectedness, acceptance, and understanding, as well as humour and laughter were frequently mentioned by participants as showing up both in the greater context of community in general as well as in the specific context of community healthcare relationships when both client and care provider were Kenhtekehró:non. Regardless of context, participants identified these values and ways of relating as being shaped largely by shared identity and growing and living together in community.

Several participants described the community as a “collective of families” sharing space. Many described community connectedness as belonging and being socially concerned with one another and each others’ families. As noted above, P03 pointed to this connectedness by asking a self-reflective question, “Am I still part of my community?” Some further described it as creating a general sense of responsibility and accountability to each other. In this way it was viewed like a support system that lends itself to community members being more apt to “help”, “share”, “cooperate”, “care” and “support” each other.

“I think with the upbringing that everybody’s had, you give back to the community because they’ve helped you. But I think that makes it bigger.” - P05

“We’re very family oriented and I don’t just mean our own families. There are things here that a lot of us disagree on but when it comes right down to it, if there’s something going on in the community, it’s like, everybody’s on board and they’re willing to go out of their way to help”

- P13

“We will just take care of you, thank you very much! For example, if there are people that are fishing in the spring, then oh, maybe so-and-so would like a fish. Or you know, somebody will come around and give you something.” - P09

Participants likewise described community healthcare relationships between Kenhtekehró:non as an extension or another facet of community connection that contributed to a sense of togetherness, belonging, comfort, support and ease in community healthcare settings.

“Going down there [to the Community Wellbeing Centre implied] with fellow natives, its the camaraderie of it. It’s more like going to visit a friend or something” - P07

“You’re not really thinking about your health. You’re thinking about visiting with somebody who understands you like family. And then you can edge right into your health.” - P15

Acceptance and understanding also emerged as values that play a central role in community healthcare relationships between Kenhtekehró:non. Participants frequently spoke about knowing each other and each other’s families and having shared experiences and intersecting lives rooted in community as deepening understanding of *each other*. Participants described this mutual understanding as a strength in the healthcare relationship, as reducing vulnerability, and contributing to feelings of trust and acceptance.

“When you get down there, you’re talking about stuff with people that just seem to know where I’m coming from. Understanding me.” - P07

“It creates a connection before you’re even connected, which I think takes the vulnerability away a little bit for our clients because they can understand a little bit about who you are as a person as opposed to just professionally. It’s all just intermingled, and you have a

different understanding of the other person as a whole and it changes the conversations that we have” -P03

“I think it’s because we know each other. That’s the comfort for me, to go to somebody that I know.” - P14

Importantly this held true for one transgender participant who likewise described feeling more understanding, acceptance and comfort when accessing care from community care providers.

“It’s way easier with people here because you know them. I found people outside they’re given a certain amount of information about you and then they’ve already got you judged right away, so they’re not as friendly or as nice to people as here” - P17

The use of humour and laughter was described by many as a community way of relating that is also brought into community healthcare relationships. Some noted that Kenhtekehró:non have a unique sense of humour, noting that poking fun at each other or the situation is understood as an acceptable way of relating, which can be misunderstood by non-Indigenous practitioners, potentially making them uncomfortable.

“I find that they don’t understand our sense of humour” - P09

“I thought it [joke implied] was funny but it was stone cold silent and then I was like oh my goodness, I’m not going to make out well here” - P25

“Ours [sense of humour implied] is mostly inappropriate and then when we laugh, really laugh it seems like it makes them nervous”. - P06

However, when used among community members it was described as a way of connecting, easing tension or stress, and creating a sense of commonality.

“We’re always laughing at each other, ourselves, our situation” - P09

“It [humour implied] just breaks the tension. It’s just making you feel good.”- P09

“You gotta have fun! That’s kind of how things go, you laugh, you cry, you come back to having fun. That’s just the way we are. You can have fun and be professional at the same time. And you get more out of people or more results and it strengthens that connection.” - P06

As described above by participant 06, engaging in humour and laughter was also viewed as a strength in the healthcare relationship and as a facilitator of positive outcomes.

5.3. Theme 3: Relationships and connection foster engagement in care

“You love us as much as we love you. And that’s the difference. Absolutely” - P13

During visits participants compared their experiences of community-based healthcare to their experiences of typical western care interactions outside of the community. They noted differences in approach to relationships of care and to the provision of care, and discussed how these differences impact their engagement in care.

Participants perceived that community care providers were more apt to relate to them from a shared foundation, or from the same level. Whereas, most non- Kenhtekehró:non care providers were perceived as relating to them from a hierarchical position of power and with paternalism. Participants used descriptors such as “on my level” or “on the same level” versus “above me” or “up there” when comparing ways of relating during healthcare interactions.

“I always like to try humor, especially if I’m nervous and try to get a little chuckle out of them but It’s like they’re not supposed to laugh or let their guard down. You know, power over you, and there’s no vulnerability. Here we’re kind of on the same level. Whereas the

other ones seem like they’re up here, looking down and talking down.” - P06

Many differentiated care providers’ ways of relating during healthcare interactions, noting that community care providers tend to be more casual or non-formal. Several alluded to the ways in which community care providers tend to move beyond arms-length professional practices guidelines to engage in closer interpersonal relationships. Several even described it as love.

“I think it is just what we do! I’ll give you an example. I have been working at [place of employment]. When I left the other day I said, I’ll see you tomorrow, okay? And they said, Yep, konnorónhkwa [I love you]! I said konnorónhkwa and I left. As I was driving, I started thinking about it. And I’ve developed this sort of relationship, where they trust me enough to not only see me again tomorrow, they actually love me, and I love them! I do love them! So that’s why I say it. Because I feel like if they need me in a professional way, then I can be that for them, but if they just need that support for a couple of minutes and they just need somebody to be there then I can do that too. I think in order to help somebody it doesn’t have to be different than it would be for you just to be you” - P03

“it’s [community care implied] way more supportive than western ways. You don’t feel like a number, you feel like a person, and it’s just so much more caring and loving” - P04

A few highlighted that this type of support is important for those who may lack support at home, or who may struggle with their health and sense of self-worth.

“For somebody like me who suffers from low self-esteem and self-worth and when you have these good connections within your community of your same people that understand how we work it’s everything! For people that maybe don’t have loving partners, or supporting family, or any family to go from having nobody to having these supports, it makes a world of difference!”-P04

In contrast, many commented that there is often no relationship at all in typical western care settings. The formal and distant professional demeanour typical of western care settings was perceived as uncaring, disinterested, unsupportive and cold.

“It felt like they just didn’t know me. Like I was just probably just another face, and it didn’t matter” - P16

“Its easy not to care about people that you don’t know” - P09

Worth noting, several mentioned having good relationships with non-Indigenous care providers both inside and outside of the community. In these cases, participants described their care providers in much the same manner as community care providers, namely, as warm, caring, interested or invested, and non-formal.

Most also differentiated approaches to care provision, noting that care provided by Kenhtekehró:non was relational, personalized, collaborative, responsive to their needs, and rooted in a deeper understanding of their lives. In contrast, typical western care interactions were perceived as authoritarian, autocratic and often consisting of a standard, rigid list of dos and don’ts.

“There [implying a western healthcare facility] it was like you’ve got to do this, this, and this. And if you don’t then more or less don’t bother coming back. But not everybody can follow the same regulations for diabetes. Everybody’s different.” - P07

“There [implying a western healthcare facility] it’s strict and by the book, versus here, I didn’t ever feel like I was going get in trouble, or scolded, or felt less than because I wasn’t necessarily taking care of myself the way I was supposed to.” - P04

Language, communication, and time management likewise emerged as important points of difference. Western healthcare interactions were

typified as being rushed and loaded with difficult to understand language and jargon that left participants feeling inadequate, frustrated, and unimportant.

“They were like ‘I have to get this done and move on’. You could feel the hurry but when our nurses come, we chat, we talk, they pet the dog, and we laugh. It’s very personal” – P11 & P12

“They talk above you, and don’t talk to you. I mean, they’re talking way up here. You’re down here. Why go waste your time If you’re not understanding what they’re trying to tell you.” - P05

In contrast, several noted that community care providers use more common, easy to understand language, speak at their level and spend time engaging in both care related and casual conversation.

“Simple English makes it so much easier to understand. And being here at home, you could ask questions and didn’t feel like it’s a stupid question” - P05

“It’s not just about my diabetes, it’s ‘how are you’ and ‘what’s going on’ and ‘are things okay?’” –P04

Grounded in generations of community connections, healthcare relationships between Kenhtekehró:non were found to foster mutual understanding, trust, comfort, ease, and belonging. Participants expressed feeling valued, important, and even loved within these healthcare relationships which had important implications on engagement with community healthcare. Many participants reporting being more apt to return for follow up appointments while others reported more open and honest communication with their healthcare provider.

“It’s a little hard to put yourself out there and talk to people, so that comfortable, cozy feeling was helpful. I could be more myself and maybe ask questions. I think it goes back to that being on the same level thing” – P06

“I enjoyed coming back because I could talk and not be afraid of what I said or did or anything because you seemed to understand.” – P16

Importantly, for some, these community healthcare relationships also facilitated motivation and engagement in self-care behaviours, including chronic disease management, beyond the healthcare interaction.

“Here I didn’t hesitate and most times I kept working at it. It kept me interested. I wouldn’t have even gone back to [outside care location]. I guess it’s the ‘I care about you’ attitude. That’s what I needed to make the change.” – P05

“You feel like they’re encouraging you to be better and be the best you can be.” – P15

6. Discussion: “We’re born to be connected” – community advisory committee member reflection

The values and norms of mainstream health services and professional practice guidelines that shape healthcare interactions are predominantly influenced by the biomedical model of care (Davy et al., 2016). The purpose of this study was to explore place based Kanyen’kehá:ka relational ethics of care and how these ways of relating may differ from typical western healthcare interactions, shape healthcare relationships, and positively impact Indigenous engagement with the healthcare system.

Overall, the participants of this study confirmed previous research on Indigenous conceptions of health, by also describing health in ways that transcend the biomedical model (CAHS, 2023; Eni et al., 2021; Hovey et al., 2014; Kennedy et al., 2022). Participants made clear that, to them, health was much more than that which could be measured by physical parameters alone and illuminated the central role of relationships, social connections, and gratitude to their health. These conceptions of health

continue to align with Kanyen’kehá:ka values and ways of being reflected in the Ohén:ton Karihwatéhkwén.

Indigenous perspectives on maintaining distance in professional-client/patient relationships tend to differ from non-Indigenous people (Hovey et al., 2014; Wilson, 2008), and for many include the centrality of connection and strong meaningful relationships. Data from this study illustrated that mutual understanding and knowing care providers outside of their professional role, as a community member, contributed to comfort and trust for participants, reduced feelings of vulnerability, and opened space in the healthcare setting for participants to be their authentic selves. Participants likewise expressed that community care grounded in relationship and connection worked in natural and fluid ways to address power imbalances typical of western care hierarchies. This blending of the personal and professional in community healthcare relationships, expressed as a strength by participants, stands in contrast to western norms of healthcare professional practice in which the personal and professional are compartmentalized and in which “arms length” relationships are the expectation.

The centrality of relationships to Indigenous ways of being reflect “a collective value of kinship based on respect and love” (Syliboy and Hovey, 2020, p E70). Indigenous Elders teach that strength lies in the capacity to love all our relations with humility, reciprocity and respect (Kennedy et al., 2022; Porter, 2008). Emerging Indigenous healthcare frameworks are beginning to incorporate love as a need of Indigenous patients and their families (Indigenous Healthcare, 2022). In our study community participants described the warm, compassionate care and love that they felt was a strength in community healthcare relationships. They described it as supportive, comforting, encouraging and motivating, all of which facilitated engagement in healthcare and importantly, for some, in self care, demonstrating the healing potential of loving relationships. Caring for and loving each other and each others’ families through community connection, responsibility and reciprocity is central to Kanyen’kehá:ka values and relational ways of being, as expressed in the Ohén:ton Karihwatéhkwén, and persists in community (Barreiro, 2010; Porter, 2008), and community healthcare, today.

In contrast, expressions of love are absent in western professional healthcare standards of practice (Maar and Shawande, 2010). This absence creates tensions not only for Indigenous community care seekers during healthcare exchanges but also for Indigenous community care providers who may struggle to balance western professional practice guidelines and expectations with their own community values and ways of relating (CAHS, 2023). Standards of western practice and expectations of professional “arms length” distance, at the cost of connection and love, diminish and marginalize Indigenous ways of being, and are inconsistent with community values and conceptions of health. Our study provides internal validation, from community, for Indigenous healthcare providers working in their own communities and who struggle between how they are trained to western standards of professional practice and their own community values and ways of caring, and confirms that the relationship, and love, that they offer is essential and central to the care.

The power and potential of healthcare relationships to mitigate past harms, mistrust and foster Indigenous engagement in healthcare has been established (Crowshoe et al., 2019; Eni et al., 2021; Jacklin et al., 2017). Participants in our study further emphasize that community healthcare relationships grounded in shared identity and community connection facilitates engagement in care. Moreover, findings reveal that, for some, these types of community healthcare relationships also facilitate motivation for self-care beyond the healthcare setting, potentially impacting health in even greater ways.

7. Implications

Recognizing and reclaiming Indigenous strengths and capacities is foundational to recovering Indigenous health. The findings from this work support the resurgence of community values and ways of being in

the context of community healthcare and for the inclusion of Indigenous relational ways of caring in contrast to western norms of healthcare professional training and practice more generally.

To optimize Indigenous health, [Browne et al. \(2016\)](#) argue for organizations to tailor policies and practices to explicitly address the needs and desires of the local community founded on the knowledge systems of the people served; our study supports this approach. For community, the findings from this work provides insights into how to engage in self-determination, moving beyond western biomedical standards of care, to define what health means, how to measure it, and how to care for the whole self and each other in ways that are congruent with community worldviews and values. Like [Browne et al. \(2016\)](#), this work demonstrates the need to move beyond western tools and frameworks for evaluating and validating Indigenous health and to develop community specific measures and indicators of health and quality healthcare that are congruent with community conceptions of health and relational ways of caring. Our findings also demonstrate the benefit of stepping outside the confines of western limits to develop programs, policies, and care delivery models that reflect community conceptions of health and care and that foster connection and relationships, regardless of western expectations or standards of professional practice; similar findings have been documented elsewhere (e.g., [Browne et al., 2016](#); [Peiris et al., 2008](#)). Finally, in expressing shared identity and community connection as a strength in the relationship of care, the findings suggest that the hiring and retention of Indigenous community care providers, from the same community, in staffing policies would work to optimize community potential and collective strengths ([Kennedy et al., 2022](#)) while facilitating engagement in healthcare.

Although the need to improve Indigenous healthcare through culturally relevant and community-based initiatives has been recognized (e.g., [Allen et al., 2020](#); [Brooks-Cleator et al., 2018](#); [Kennedy et al., 2022](#); [Richmond and Cook, 2016](#)), not all healthcare is provided in community and non-Indigenous care providers will continue to play an important role in Indigenous health ([CAHS, 2023](#); [Browne et al., 2016](#); [Nguyen et al., 2020](#)). The findings from this study show the same and have implications for healthcare professional education and training more generally as our data reinforces the need for strategies targeting approach to Indigenous care seekers and to healthcare interactions to foster Indigenous engagement in care. Our findings also underpin the need to change education, training, policy, processes, and current standards of professional practice to allow space for Indigenous values, and conceptions of health including relational ways of caring ([Brooks-Cleator et al., 2018](#)) that are disapproved of by western norms of care such as “arms-length” and the compartmentalization of care. The inclusion of Indigenous values and relational ways of caring in healthcare professional education and training would work towards establishing cultural safety not only for Indigenous seekers of care but also for Indigenous healthcare providers who may feel caught between western biomedical professional practice standards and their own community values and ways of caring.

Further Kanyen'kehá:ka research is needed to understand why some community members choose to access care outside of the community; this would deepen scholarly and applied understandings of facilitators and barriers to Indigenous engagement in healthcare. Additionally, the study's focus on Kanyen'kehá:ka and specifically Kenhté:ke values and ways of caring may raise questions about generalizability. However, given the similarities in barriers to Indigenous healthcare engagement worldwide ([Gracey and King, 2009](#)), the findings from this study may provide insights for other Indigenous communities and community care providers as they continue to recover and rebuild community health and ways of being. This study also offers insights for healthcare providers more generally on facilitating Indigenous engagement in care, from Indigenous people, by Indigenous people.

As demonstrated here, Kanyen'kehá:ka values and ways of relating are inherently non-hierarchical. Every effort was made to ensure participant comfort; yet the ongoing influence of colonial ways of being

may have influenced willingness to participate. Additionally, limited anonymity in a small community may have impacted participant ease in voicing negative community experiences, and relations of interpersonal or professional power may have been at play, potentially impacting the findings. Further, while the participant sample largely represents the population accessing services, increased inclusion of male, youth, and gender non-conforming members would strengthen future research. Lastly, research into whether Kanyen'kehá:ka care, by and for Kenhtekehró:non, results in improved health outcomes and reduced disease burden is sorely needed to create the kind of positive policy reform and transformational change in practices needed in the Canadian healthcare system.

8. Conclusion

Despite efforts within the healthcare sector to create culturally safe and equitable care, Indigenous Peoples continue to face barriers to engagement in mainstream Canadian healthcare including racism and the marginalization of Indigenous values, conceptions of health and relational ways of being ([Allan and Smylie, 2015](#); [Reading and Wien, 2009](#)). Evidence suggests that strong relationships of care hold the potential to foster and maintain Indigenous engagement in healthcare ([Jacklin et al., 2017](#); [Crowshoe et al., 2019](#); [Walker and Behn-Smith, 2018](#)). The findings from our study demonstrate that strong relationships of care foster and facilitate engagement in community-based healthcare and motivates self-care beyond the care interaction. Further this study deepens our understanding of the substance of these relationships that step beyond western biomedical notions of care and professional practice standards to engage with Indigenous values and conceptions of health and ways of caring.

CRedit authorship contribution statement

Jodi John: Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Heather Castleden:** Writing – review & editing, Supervision.

Ethics approval

Ethics approval was granted by the General Research Ethics Board (GREB) at Queen's University.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

The data that has been used is confidential.

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