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Welcome to the First Edition from Waakebiness-Bryce Institute for Indigenous Health

The Waakebiness-Bryce Institute for Indigenous Health (WBIIH) is thrilled to produce its first volume of the International Journal of Indigenous Health (IJIH). At the WBIIH, work in research, training, and policy development is grounded in Indigenous knowledges and community partnerships. Indigenous knowledges have been used globally since time immemorial. These knowledge systems evolve and adapt over generations, yet remain consistent in that they view animals, plants, water, air, humans, and all creation as equal within the cosmos; throughout this volume, the reclaiming and proclaiming of Indigenous knowledges is a thematic basis for improved health and well-being of Indigenous peoples.

Theories and programs for Indigenous health from around the world continue to populate the literature and identify “best practices,” yet there is little discussion of the measure by which these practices are drawn. Specifically, many of these practices and models are made to fit within non-Indigenous biomedical and clinical settings. What is Indigenous health from Indigenous perspectives and how can biomedical health care systems and researchers make room for it? The onus of understanding and working with issues of Indigenous health and research rests with all peoples, particularly non-Indigenous peoples, as all people reside on traditional Indigenous lands and within the context of current and historical treaties and agreements with First Peoples worldwide. Statistical data amply supports the “failures” of Indigenous people’s health yet little data enlightens with solutions and successes based on Indigenous knowledges and healings practices.

This volume of the IJIH fills this knowledge gap by identifying the strengths and solutions of Indigenous knowledges in biomedical and service health systems. There are nine articles in this issue that cover numerous topics in Indigenous health. Yet one theme that emerges across articles is the revitalization and inclusion of Indigenous knowledges, specifically in areas of healing, medicines, and integration of Indigenous ways of knowing in biomedical health care. Through a critical interrogation of the dominant discursive regimes of both Indigenous and biomedical health care theories in various
clinical discourses, this volume explores the nature of research, theory, and practice in relation to patients or data, focusing particularly on how individuals and groups construct illness perceptions and the kinds of treatments they expect will solve health problems. In this respect, this volume can also contribute to wider debates about minority health, health care, and research. Contributors are leading researchers within the multidisciplinary field of Indigenous health, representing health disciplines of psychology, psychiatry, nursing, and social work. These contributors submitted empirical research papers on topics related to Indigenous healers, cultural healing practices, the integration of Indigenous and Western healthcare practices, the healing encounter, professional training and education, Indigenous research methodology, and ethical considerations for conducting research.

All articles in this volume share themes related to traditional Indigenous knowledges, cultural identity, racism and oppression, healing, intergenerational trauma, mentoring, and modeling. Implications related to health care workers, administrators, educators, and policy makers illuminate the context of the articles, including the importance of community collaboration, changing policy and protocols, and negotiating tensions between Western and Indigenous theories and practices. Ultimately, attending to Indigenous issues and incorporating cultural practices in health can serve to enhance and improve Indigenous peoples’ needs, but these can also benefit non-Indigenous people’s experiences and outcomes in health care, many of whom are also failed by the current Eurocentric, colonial system of health.

The Editors encourage scholars in Indigenous health research from around the world to submit articles to the IJIH for upcoming issues. It is important to hear about Indigenous health and well-being from different countries to make systemic and institutional changes for Indigenous peoples.

Miigwetch / mahsi cho

Dr. Suzanne L. Stewart
Dr. Angela Mashford-Pringle
Co-editors in Chief, IJIH

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Aboriginal Youth Experiences with Cyberbullying: A Qualitative Analysis of Aboriginal e-mentoring BC

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Aboriginal Youth Experiences with Cyberbullying: A Qualitative Analysis of Aboriginal e-mentoring BC.

Abstract
Technology has transformed interactions among adolescents from face-to-face to instantaneous virtual communication. Yet the use of digital media among adolescents can be potentially harmful with the risk of cyberbullying. While cyberbullying is a growing concern, few researchers have explored cyberbullying experiences among Aboriginal adolescents. The present study addresses this gap by examining qualitative data regarding cyberbullying experiences provided by Aboriginal youth participants between ages 11 and 17 in Aboriginal e-mentoring BC, which was an internet-based mentoring program in the province of British Columbia, Canada. The analysis of the data highlighted 4 themes: (1) perceptions and use of technology, (2) awareness of online safety and netiquette, (3) cyberbullying prevalence, and (4) prevention and coping skills. Transcending these themes was the importance of Aboriginal perspective and knowledge in mentoring and anti-cyberbullying initiatives. The results of the work presented in this study highlight the potential benefit of incorporating online safety and technology use in interventions to promote wellbeing among Aboriginal youth. The study findings on Aboriginal adolescents’ online experiences and perceptions of online safety can assist researchers and Indigenous health providers to better understand the cyberbullying phenomenon.

Keywords
Cyberbullying, cybervictimization, Aboriginal, adolescence, mentoring, information and communication technology (ICT)

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Introduction

While there are considerable positive uses of digital media, the advent of widespread technology use raises concerns about cyberbullying (Tokunaga, 2010). Cyberbullying refers to any behaviour carried out by a group or individual through electronic devices or digital media to repeatedly post hurtful messages to others (Tokunaga, 2010). Cybervictimization refers to individuals or groups being a target of online aggression (Shapka & Maghsoudi, 2017). Empirical studies have shown that cyberbullying experiences (as either bully or victim) are often associated with mental health problems, such as anxiety (İçellioğlu & Özden, 2014), substance misuse (Fisher, Gardella, & Teurbe-Tolon, 2016), depression (Wang, Nansel, & Iannotti, 2011), and suicide ideation (Bonanno & Hymel, 2013). While cyberbullying is a growing issue, there is a paucity of research focused on cross-cultural cyberbullying experiences across youth populations (Cross et al., 2015). The aim of the present study was to explore Aboriginal adolescents’ perceptions about online safety and their cyberbullying experiences.

Influence of Colonialism on Aboriginal People

“Aboriginal people” is used to describe the Indigenous people of Canada who self-identify as First Nations, Métis, and/or Inuit. While there are educational and health initiatives to ameliorate devastating colonization practices in Canada, many Aboriginal people continually experience health issues, learning difficulties, and/or intergenerational trauma (Health Canada, 2014; Jongbloed et al., 2017). For example, it is possible that Aboriginal youth are targeted for bullying and other aggressive acts due to discrimination associated with their minority status (Melander, Sittner Hartshorn, & Whitbeck, 2013). Melander et al. (2013) conducted a longitudinal study among 702 North American Aboriginal adolescents in the United States exploring the link between discrimination and aggression. Their study found a positive association between perceived discrimination and aggressive delinquency, which was partially connected with feelings of anger. In Australia, Aboriginal people were more likely to be targeted for online hate speech in comparison to non-Aboriginal people (Oboler, 2012). Further, social media sites, especially Facebook, were used in online aggression targeting Aboriginal people. Given Aboriginal people were more likely to be discriminated against online, it is possible that online hate speech may also be linked with other types of aggression, such as cyberbullying, experienced by Indigenous adolescents. To the best of our knowledge, there is no research on cyberbullying for Aboriginal youth. As such, the background for this study has been guided by adolescent cyberbullying trends in general.

Hugunlht’ih (How are things?): Exploring Cyberbullying Trends

Cyberbullying is a growing public health concern that has considerable impact on adolescents, families, and communities with both immediate and long-term consequences (Carter & Wilson, 2015; Fisher et al., 2016). Yet there is substantial variability in prevalence rates of cybervictimization, ranging from a low of 6% to a high of 74% (Hamm et al., 2015). Similarly, prevalence rates of cyberbullying others vary, ranging from 6% to 29% (Hamm et al., 2015). Past findings indicate youth in Grades 8 and
were more likely than other grade levels to report cybervictimization (Sampasa-Kanyinga & Hamilton, 2015).

Longitudinal evidence shows that attitudes, anonymity, and online behaviour are unique risk factors for later cyberbullying behaviour and attitudes (Barlett & Coyne, 2014). Cyberbullying may include utilizing technology to send threats, ostracize others on social media, and/or post abasing digital media content (e.g., text, picture, or video). Furthermore, the initial hurtful post may “go viral” if online bystanders repost, share, or forward the cyberbullying incident (Slonje, Smith, & Frisén, 2013). Cyberbullying is not restricted by time and space with the relative permanence and public availability of digital media (Tokunaga, 2010).

Some studies suggest there are several coping strategies youth may employ given their perceptions about online safety behaviours (Cerna, Machackova, & Dedkova, 2015). For example, young people commonly utilize technical coping strategies to deal with cyberbullying incidents, such as changing usernames, passwords, or mobile numbers (Cerna et al., 2015; Perren et al., 2012). Empirical evidence from a Canadian study found that adolescents who experience cyberbullying are less likely to seek help from adults or others, but if they do tell, their preference is to tell a friend, then a caregiver, and lastly school staff or a teacher (Cassidy, Jackson, & Brown, 2009). These various online safety behaviours and coping strategies need to be further explored to better tailor supports for diverse adolescent populations.

Indeed, the advent of Wi-Fi and mobile devices has shifted the nature of social interactions such that concerns about online safety and cyberbullying have become a worldwide concern. Although there is a burgeoning cyberbullying literature, which has online safety implications, there is a dearth of research exploring Aboriginal adolescents’ online experiences. To better understand this complex issue, the current study explored online safety behaviours and cyberbullying reported by Aboriginal youth. Insight into how Aboriginal youth perceive the appropriateness of their online actions and engage in social media may raise awareness of a broad range of cybersafety issues. The main research questions that guided the present study included: (1) What are Aboriginal youth perceptions about online safety behaviours? and (2) What are Aboriginal youth experiences with cyberbullying?

Methods

Data Collection

The data were obtained from the Aboriginal e-mentoring BC program, an internet-based mentoring program developed with initial funding from the Canadian Institutes of Health Research. The Aboriginal e-mentoring BC research team consulted with several First Nations communities and school districts in the province of British Columbia, Canada, to partner in the program (for more information see: http://www.aboriginale-mentoringbc.ca/about-us/our-story/). The research design was informed through collaboration and consultation with members of partner First Nations and school districts.
Aboriginal e-mentoring BC began in 2009 with a focus on connecting Aboriginal youth with mentors in postsecondary health sciences programs throughout the province. The Aboriginal e-mentoring program is conducted on a secure, password-protected hosted on a partner platform. The mentees and mentors engaged in a curriculum, titled the “Personal Quest,” which included online modules focusing on goal setting, internet safety, study habits, and career goals for a 1- to 2-hour weekly commitment during one school year or semester. The partner platform allowed participants to register by creating usernames with no personally identifying information, and online conversations underwent an advanced automatic filtering system that removed sensitive information. This platform allowed participants the convenience of logging in at any time to participate as the program functioned in an asynchronous manner.

The data used for the present study analysis were based on discussion transcripts gathered as part of the data collection from the Aboriginal e-mentoring BC program during the 2011–2014 academic years. The relationship between the present study and Aboriginal e-mentoring BC program is that of the latter providing the former with discussion transcripts between mentees and mentors for data aimed at understanding cyberbullying and online safety behaviours reported by Aboriginal youth. The data collection for the discussion analysis occurred throughout the duration of the Aboriginal e-mentoring BC program. Discussion transcripts were downloaded from the partner platform monthly and did not include any personal identifying information. A self-report demographic survey was delivered to participants at intake into the Aboriginal e-mentoring BC program. Designed as a community-university partnership, the program established First Nations band and school district agreements to meet each partner “where they are” to adapt the delivery of the Aboriginal e-mentoring BC program in their community or school. Research agreements, with the guidance of First Nations communities, outlined the parameters of the Aboriginal e-mentoring BC program in their respective community or school. The present research received institutional approval from the University of British Columbia Behavioural Review Ethics Board.

Participants

To be eligible as mentees for the program, participants had to be in Grades 6 to 12, as well as self-identify as Aboriginal (First Nations, Inuit, or Métis). Self-identification invited adolescents to voluntarily identify as First Nations, Métis, or Inuit. Thus, no proof or documentation of heritage was required. For mentor eligibility, participants were between ages 18 and 35. Mentors needed to commit to 1 to 2 hours per week to connect with a mentee online, for the duration of one school year or semester. Mentors were enrolled in or recently graduated from a postsecondary health science program in British Columbia and desired to support Aboriginal youth in achieving personal, educational, and career goals.

The recruitment strategy involved working closely with Aboriginal communities and postsecondary institutions located throughout British Columbia to identify and encourage Aboriginal youth (mentees) and health sciences students (mentors) to participate. Members of the research team
engaged with youth in variety of ways, such as in-person visits to their school or home community, to inform them of the program and to obtain their assent to participate. Furthermore, the research team engaged with stakeholders identified by First Nations communities and school districts who acted as leads for the Aboriginal e-mentoring BC program (e.g., guardians, teachers, school administrators, chief and council, band education coordinators, and families). These stakeholders ensured that the program took into consideration cultural protocols and community needs, such as access to technology and support. The research team made every effort to obtain written consent from guardians for research participation. Adhering to Canadian Institutes of Health Research (2013) guidelines for health research involving Aboriginal people, as well as acknowledging cultural significance, guardians who were unable to provide written consent were able to give oral consent over the phone, recorded by a researcher on a hard copy of the oral consent protocol. All participants were provided with a copy of the consent form for their records. In order to protect privacy and confidentiality, pseudonyms were used throughout the study.

Data Analysis
Throughout the 3 academic years examined, mentees contributed a total of 4,611 unique text submissions. These “units” of conversation were related to one of several topics in the Personal Quest, each of which had a different focus, but all were generally related to exploring career goals and academic pathways in which to reach them.

A thematic content analysis of online mentor-mentee transcripts was conducted to address the research questions. During the first stage (open coding), the transcript data were chunked into small units. The research team attached a descriptor, or code, to each of the units. Then, during the second stage (axial coding), these codes were grouped into categories. In the third and final stage (selective coding), the research team developed themes that express the content or core themes of the discussion content. A codebook was created from all the data sources. Data were coded and analyzed using NVivo 9.

Results
Sample Characteristics
A total of 189 mentees and 119 mentors joined the Aboriginal e-mentoring program over a 3-year period (see Table 1) and were included in the current study. For mentees, 93 (49%) were young women and 96 (51%) were young men. In comparison, the 2011/12 British Columbia Ministry of Education statistics indicated similar rates of female adolescents (49%) and male adolescents (51%) enrolled in provincial public secondary school across Grades 8 to 12 (Province of British Columbia, 2014). Mentees were Aboriginal students in Grades 6 to 12 across urban and rural areas, including Aboriginal reserves, throughout British Columbia. The largest numbers of mentee participants were in Grades 6 and 7 (37%) at the entry of the study and from an urban community (77%). Mentors were postsecondary students or
recent graduates primarily in health sciences programs. Approximately one third of mentors identified as having an Aboriginal heritage.

Mentees logged a total of 22,179 minutes on the online mentoring platform talking to their mentors. Active mentees communicated on the Personal Quest with their mentors between 1 and 117 times ($M = 28$). Similarly, 101 mentors communicated between 1 and 96 times ($M = 20$).

The thematic content analysis of all conversations resulted in a total of five themes which included 19 distinct categories. The current study is an initial analysis of discussion transcript data gathered from the Aboriginal e-mentoring BC program. The results are focused on one of the themes that emerged—cyberbullying. Units of analysis in this theme included written responses by mentees that included one of the following relevant search terms: bully ($n = 67$), bullies ($n = 6$), cyberbully ($n = 14$), netiquette ($n = 8$), online ($n = 56$), technology ($n = 5$). A total of 156 units were included in the analysis. The following results highlight mentees’ experiences with cyberbullying and are organized into four subthemes: (1) perceptions and use of technology, (2) awareness of online safety and netiquette, (3) cyberbullying prevalence, and (4) prevention and coping skills. Each is operationally defined below in relation to how mentees discussed them, and illustrative quotes are provided.\(^1\)

**Themes**

**Perceptions and use of technology.** This theme includes mentees’ reported use of technology and online resources, frequency of going online, and purposes of going online. Youth reported spending anywhere from 2 to 8 hours online per day. The amount of time per day increased when youth were bored, or when the internet provided resources related to a specific interest of theirs (e.g., gaming). By far, the most reported purpose of going online was to use social networking sites including Facebook, Tumblr, and Snapchat. One mentee stated, “I spend about 2 or 3 hours a day on the internet, except when I’m bored it could be anywhere around 5–8 hours. I have a Twitter, YouTube, Instagram, Facebook, Tumblr, and Snapchat” (emilytara1, line 3102).

On rare occasions, mentees mentioned that their parents monitored what they posted online, but many youth reported they had at least some independence when it came to their use of technology and social media.

**Awareness of online safety and netiquette.** This includes mentees’ self-reported perceptions on the safety of their behaviours online, whether mentees shared personal and/or identifiable information online, and whether they understood the potential career repercussions of sharing personal information online.

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\(^1\) Note that some spelling errors within quotes have been edited for clarity.
Mentees generally reported they were aware of online safety concerns. Indeed, not a single mentee said they didn’t understand what online safety is. One mentee stated: “I try to be careful about what I release on to the internet, I’m well aware that once it is out there, it’s always out there” (2sarah2, line 12).

Table 1
Aboriginal e-mentoring BC Program: Mentee and Mentor Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sample size</th>
</tr>
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<tr>
<td>n</td>
<td>%</td>
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<tr>
<td>Mentees^</td>
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<tr>
<td></td>
<td>189</td>
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<tr>
<td>Gender</td>
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<tr>
<td>Female</td>
<td>93</td>
</tr>
<tr>
<td>Male</td>
<td>96</td>
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<tr>
<td>Participants by year</td>
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</tr>
<tr>
<td>2011/12</td>
<td>63</td>
</tr>
<tr>
<td>2012/13</td>
<td>45</td>
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<tr>
<td>2013/14</td>
<td>81</td>
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<tr>
<td>Grade level (at entry)</td>
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<td>6</td>
<td>38</td>
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<td>11</td>
<td>16</td>
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<tr>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Geographic location</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>44</td>
</tr>
<tr>
<td>Urban</td>
<td>145</td>
</tr>
<tr>
<td>Mentors</td>
<td>119</td>
</tr>
<tr>
<td>Heritage</td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>40</td>
</tr>
<tr>
<td>Other</td>
<td>79</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
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<tr>
<td>Female</td>
<td>80</td>
</tr>
<tr>
<td>Male</td>
<td>39</td>
</tr>
</tbody>
</table>

^ Differences in sub-total proportion reflect those participants that did not respond to items.

Mentees were also able to recite principles of online safety, including “only talk with people that you know well, don’t give out your personal information to strangers, don’t insult people online”
Some mentees were also adept at implementing strategies to ensure they remained anonymous. For example, one youth stated that they alter their information:

*Mainly I use fake birth dates, not too far off, but close enough. I never post anything mean, although I will defend myself any way necessary (should the need arise). I never give my [address] (unless it’s a trusted site).* (Epsilon, line 587).

However, occasionally, even when mentees knew about netiquette principles, they discussed breaking their own guidelines.

*I must admit that in the past, when I was young and less mature, I did break some netiquette rules. Now however, I wonder how in the world I was so immature. I have also experienced some bad netiquette myself, a lot in fact.* (Tiger2014, line 513).

Mentees also expressed an awareness of the implications of using technology inappropriately, stating that it could hurt their chances of securing employment, or affect the way other influential adults perceive them (e.g., teachers).

*Things that people write such as personal information, posting pictures, and swearing or using inappropriate language in their statuses can keep them from getting jobs because nowadays businesses look at their employees’ profiles.* (amysharon, line 147).

*Also, things you post online could affect how peers and teachers think of you too, because if you post a bunch of stupid things like videos of you drinking or smoking weed they’ll think that you’re not a serious person and shouldn’t be hung around with.* (LeeshaF, line 1123).

**Cyberbullying prevalence.** This theme includes mentees’ experience with cyberbullying, including self-reports on whether they had been the victim of online bullying by a peer or stranger. Although many mentees articulated an awareness of online safety and netiquette, mentees did report instances of either experiencing or witnessing face-to-face or online bullying. Only 34 mentees stated that they had no experience with bullying of any sort. While some mentees simply stated they had experienced cyberbullying, 13 youth spoke specifically about their experiences with being victimized by online bullying.

*I personally have been cyber bullied, I guess. A couple of months ago a friend of mine and I took funny pictures of the two of us. I asked her not to put them...*
on [social media site], but she did anyways and about 12 of my friends posted a very unattractive photo of me as their profile pictures. (amysharon, line 444).

Other mentees discussed not personally being cyberbullied, but witnessing it happen to someone else. Sometimes witnessing cyberbullying occurred on almost a daily basis:

When you look on [social media site], every single night you will notice a lot of the youth are being so rude to each other, posting pictures of someone and letting everyone comment rude things about them, where it comes to the point you see statuses on [social media site] where young people are talking about hurting themselves or how much they hate their life. It’s embarrassing knowing that you know those people who are doing the bullying, even worse when you feel the embarrassment from other people writing comments about that one person they don’t like, it’s almost like you can feel what the victim is feeling. (wordless1, line 444).

One youth articulated the severity of the issue:

I actually think that this is a big issue for a lot of teens in this generation because we were born into technology, and because of that we rely too much on it. Which means we take advantage of it, it gets used for homework, studying or doing such things as e-mentoring but it’s also used to bully and harass people in a rude and inappropriate manner. (wordless1, line 4476).

Mentees were quick to realize that one of the reasons why people are more likely to bully others online is because of the anonymity and distance that the internet provides: “I’ve noticed that people are more open online because they think that no one will ever know it’s them doing the talking, or they think that what they post won’t affect them in any way” (Line 1123, LeeshaF).

**Prevention and coping skills.** One question in the Personal Quest asked mentees to report what they would do if they were cyberbullied or witnessed someone else being cyberbullied. Within this question, some mentees talked about the negative impact cyberbullying had on them, including its being “very stressful and it was just downright horrible” (Kendra12171, line 925). One mentee acknowledged how difficult it was at the time, but that they gained perspective over time:

I was once the victim of cyberbullying. Now that I look back, I realize it wasn’t that big of a deal, but at the time it seemed like the worst possible thing that could happen to me. The girl was in my class, and she acted like nothing was going on while we were in the same room, but as soon as I left she’d spread
Mentees reported various coping strategies, including the following: reporting the post to a friend or adult (e.g., teacher, parent, principal, school counsellor, police), deleting their account or enhancing their security settings so that people were not able to post things about them, ignoring the person completely until they got bored with a lack of response, or standing up for themselves by “talking to the person in the nicest way possible that it is wrong to talk about people online” (deerbear103, line 74). One mentee talked about how they stood up for themselves in the past:

Yes, I have been cyber bullied online, and I’ve won most of the fights because of the ways of handling it. With me, it’s talking back, not rudely, but with logic, do it in a calm way, and don’t give them anything to use against you. (Naktarra, line 1396).

One mentee also suggested that everyone should think before they post and not post anything they may regret later. Another suggested that a presentation made by youth would be helpful:

I think it would just be good if there was actually a presentation made by a youth and presented by youth about these problems because we hear this all the time and how it’s bad, but when something so negative is presented by a student to others I think it actually hits us. (wordless1, line 10).

Discussion

To our knowledge, this is the first study to focus on cyberbullying experiences among Aboriginal youth in addition to their perceptions of technology, netiquette, and online safety. The findings highlighted four themes: (1) perceptions and use of technology, (2) awareness of online safety and netiquette, (3) cyberbullying prevalence, and (4) prevention and coping skills.

First, for perceptions and use of technology, we found these Aboriginal youth spent 2 to 8 hours online per day, increasing to the upper end of the range when they were bored or when accessing the internet related to their personal interests (e.g., gaming or social networking sites). Balakrishnan (2015) found adolescents who spent 2 to 5 hours online per day were more likely to be involved in cyberbullying in comparison to teens who spent less than an hour online each day.

The second theme, awareness of online safety and netiquette, revealed all participants understood what online safety involves. Study findings suggest that these Aboriginal youth often voluntarily overshared personal information in online contexts. Aboriginal teens have made decisions about sharing personal information on social media sites based on their perception of public accessibility by employers.
and others. Past research found anonymity and publicity moderates the severity of cyberbullying (Dredge, Gleeson, & de la Piedad Garcia, 2014). Aboriginal youth participants shared that not knowing who can access personal information online as well as observing what their peers post online influenced their perceptions of the appropriateness of online behaviour.

The third theme of cyberbullying prevalence revealed that Aboriginal youth have an awareness of cyberbullying. Participants shared either experiencing or witnessing face-to-face or online bullying. Those that did share about online interactions reported witnessing cybervictims talk on social media about self-harm and an unhappiness with life. Consistent with empirical evidence, cyberbullies and cybervictims commonly report depressive symptomatology, and in extreme cases, suicide ideation (Bonanno & Hymel, 2013) or suicide (Hinduja & Patchin, 2010). Our findings suggest a troublesome concern related to young Aboriginal people’s wellbeing and cyberbullying victimization.

Finally, the prevention and coping skills theme revealed Aboriginal youth utilized various strategies, such as problem-focused (e.g., seeking help from others or confronting the cyberbully), technical (e.g., enhancing security settings), and avoidant (e.g., ignoring the person). Further, as in other research, factors found to safeguard youth included interpreting the experience as a joke and believing that others experience cyberbullying (Dredge et al., 2014). Our findings indicate Aboriginal youth respond to the threat of cyberbullying by using a combination of cognitive and behavioural coping strategies.

Future Directions and Limitations

Implications of this study’s findings have the potential to make meaningful transformations in the lives of many Aboriginal adolescents as healthcare providers and educators shift how they engage Aboriginal youth in health promotion strategies and educational programs. In terms of applied implications, by training healthcare providers and educators working with Aboriginal communities to recognize and respond to technology use by teens, they may be better able to engage Aboriginal youth in innovative social support services, such as online mentoring programs. Moreover, investigating the link between online safety behaviours and cyberbullying has meaningful implications for understanding how Aboriginal teens reveal themselves to others on social networking sites.

Further research exploring the relationship between cyberbullying and online safety behaviours reported by Aboriginal adolescents can provide insight into the coping strategies teens use to safeguard against and appraise the threat of cyberbullying. Yet further research on the help-seeking behaviour of Aboriginal youth faced with cyberbullying is needed. Gaining further insights into the relationship between how Aboriginal adolescents respond to and cope with cyberbullying is essential for health and school programmers if they are to help teens navigate privacy concerns about sharing personal information and how to safeguard against online risks.
This study provides insights into Aboriginal youth cyberbullying and cybervictimization experiences. Yet there are potential study design aspects that may limit conclusions. For instance, only transcript data were obtained and not direct measures of cyberbullying behaviour. As well, the results do not provide insights into the casual or correlational associations between negative online experiences and coping strategies. Longitudinal research is needed to explore the relationship between negative online experiences, coping strategies, and Aboriginal youth wellbeing. Given educational and healthcare efforts to raise awareness about issues of online safety behaviours, longitudinal research can provide insight into coping strategies and online risks (e.g., cyberbullying or cybervictimization) to better inform how we are educating Aboriginal youth.

The seeming ubiquity of sharing digital media content (e.g., pictures, texts, videos) online among young Aboriginal people, its link with cyberbullying, and the continued rise in technology use make culturally relevant and developmentally appropriate interventions an urgent matter. Additional research on Aboriginal youth’s online experiences is needed to better inform the creation of culturally appropriate educational resources.

Conclusion

This study aimed to provide a better understanding of Aboriginal youth’s cyberbullying experiences and privacy concerns. The findings revealed Aboriginal youth are often aware of online safety and netiquette. Yet several Aboriginal youth in the study experienced or witnessed cyberbullying and/or cybervictimization on social media. Additional rigorous investigation of young Aboriginal people’s cyberbullying experiences as victims and/or bullies is needed. Overall, to raise awareness of diverse cybersafety issues, there is a need to better understand how Aboriginal youth mobilize social resources and use digital media in the face of cyberbullying.

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Milo Pimatisiwin Project: Healthy Living for Mushkegowuk Youth.

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Abstract
The Milo Pimatisiwin Project is a community-centred initiative of John Delaney Youth Centre in the Moose Cree First Nation community in the James Bay region, Ontario, Canada. This article describes the creation of this collaborative youth-centred project and how it re-centres Indigenous values and conception of health and wellbeing. The article begins with an overview of the Cree philosophy of milo pimatisiwin, “good and healthy living.” This sets the background for the focus of the article, namely the significance of sharing pimatisiwin teachings over the local youth radio station and within land-based initiatives. The study includes the project results and feedback from the youth engaged in the project. It also describes the Youth Services Director’s vision and leadership efforts to enhance culturally relevant programming at the Youth Centre. Finally, it discusses lessons learned in the project and suggests best ways to enhance wellbeing in community-engaged research initiatives. The aim is to privilege Indigenous people, their knowledge and experiences, and their critical role in decolonizing notions of health and wellbeing within research practices and community-centred initiatives.

Keywords
Community-based participatory research, Moose Cree First Nation, youth and community wellbeing, milo pimatisiwin.

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Introduction

The fact that we have them [the pimatisiwin teachings] is a huge step in sharing traditional values, beliefs, and stories with modern technology. This has helped create a launch pad for future cultural programming at the Youth Centre. The radio allows people to listen and learn anonymously, which can be a wonderful way to start for beginners. (Youth Services Director, John Delaney Youth Centre, Moose Cree First Nation).

Entire generations of Indigenous people have missed out on cultural teachings that were typically transmitted orally through stories, experience, observation, and Elders. Intergenerational stressors, including residential schools and encroachment on land and resources with little consideration for the use of the land for the future are some of the factors that have led to this gap in knowledge exchange. Indigenous Peoples’ connection to the land has long played a vital role in sustaining their kinship structures, cultural practices, and subsistence economies. Hence there has been a re-emergence of returning to the land for healing, rebuilding, and remembering (Radu, House, & Pashagumskum, 2014; Robbins & Dewar, 2011; Simpson, 2011, 2014; Simpson & Coulthard, 2014; Wildcat, McDonald, Irlbacher-Fox, & Coulthard, 2014; Wilson, 2003). The importance of this connection provides the impetus to revitalize land-based practices—in this instance milo pimatisiwin, the Cree holistic conception of being well and living well.

This article presents a collaborative (academic–community) project that emerged out of a participatory research with Moose Cree First Nation in Moose Factory, Ontario, Canada. Moose Factory is on an island in the southern end of James Bay. There are approximately 2,500 people who live on the island; 974 are youth under the age of 17. Since time immemorial, the Omushkego lifestyle was intimately tied to the land and to family. The people lived with their environment, making best use of the abundant land and water, food, and material resources. With the profound cultural changes emerging from various factors, the land lifeways also changed, including the transmission of survival skills and knowledge between generations (Flannery, 1995; Long, 2010).

We explored the way in which the milo pimatisiwin concept informs youth programming. The purpose is to contribute to the understanding of milo pimatisiwin and its practical application to community and youth wellbeing initiatives launched as part of a collaborative approach to research. We begin with background information, including a Moose Cree perspective on the concept of milo pimatisiwin and a review of existing literature. Next we present the project context, with an overview of the project phases; methodology; and results, with feedback from youth involved in the project. The Youth Services Director’s vision further leads us to the best ways to foster health and wellbeing for youth. Finally, we discuss lessons learned in the project and offer concluding reflections.
We (the two authors) come from different Indigenous identities, places, and professional roles. Yet we both have uniquely experienced and felt the loss of connection to land and life-stage teachings. In our respective journeys, we have started to relearn and to reassert the life-stage teachings in our personal and professional lives. Given our shared passion and understanding of the significance of these teachings to individual and collective wellbeing, we are committed to helping our families and communities acquire the knowledge needed to grow our life-knowledge bundles and to make it applicable in a current social context. We further saw this collaborative project as a part of our life-stage responsibility as adult women.

Background: The Good Life Tapestry

*Everything was integrated in the pimatisiwin teachings: governance, justice, spirituality, family, and community was part of it. It was done in accordance to the world around us and the seasons. We did not try to fit the world around us and we fit into it. We cannot schedule fasting until the buds formed around the trees. We worked with the natural cycles. The land told us when to do these things.* (Youth Services Director, John Delaney Youth Centre, Moose Cree First Nation).

A Moose Cree Understanding of Milo Pimatisiwin

The Moose Cree concept of *milo* means “good” while *pimatisiwin* translated literally means “life.” “Cree is polysynthetic. This means that a single word in Cree can express complex ideas that would need many separate words in other languages.”² Descriptively translated, milo pimatisiwin represents the cyclical nature of life and provides guidance on how to live in right relationship with self, community, and nature. The belief is that pimatisiwin teachings are a necessary part of asserting sovereignty over one’s right to living and being well. The holistic meaning of pimatisiwin situates one’s place of belonging, roles, and responsibilities articulated in the life rites of passages and kinship relations. Connection to the land is central to the cultural practices, rituals, stories, and ceremonies of Omuskego people.

Literature Review: A Broader Understanding of Milo Pimatisiwin and Its Practical Application

Milo (or mino) pimatisiwin is often regarded as an interconnected worldview of living and being well (Adelson, 2000; Anderson, 2011; Hart, 2010; Radu et al., 2014). “A worldview is the overall perspective from which one sees, experiences, and interprets the world” (LaBoucane-Benson, Gibson, Benson, & Miller, 2012, p. 5). Milo pimatisiwin is respected as a lifelong continuous learning process, in constant motion and interaction with the land (Radu et al., 2014).

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² Description of the Cree language came from a Moose Cree book launch event in Moose Factory, Ontario, on August 7, 2015.
The term *milo pimatisiwin* is not unique to Cree people. The Ojibwe people also use *pimadiziwin* to describe the central value of health and wellbeing (Manitowabi & Shawande, 2011). *Mnaamodzawin* is equivalent for the Anishnabe people of Manitoulin Island, Ontario. It means a “good, holistic way of life” (Manitowabi & Shawande, 2011). Despite the different terminology, common values and common understanding weave the good life tapestry. “This is a term used to describe holistic health and wellness, including physical, emotional, mental and spiritual stages of being” (Anderson, 2011, p. 7). Leanne Simpson (2011) explains how the knowledge of *mino bimaadiziwin* [the good life] exists in Indigenous theory, Creation stories, teachings, and experiences. She further explains how living in an identity grounded in the land “propels us towards mino bimaadiziwin” (p. 13).

In the last decade, Indigenous researchers have contributed to the contemporary use of the concept of milo pimatisiwin (Hart, 2010; LaBoucane-Benson et al., 2012; Radu et al., 2014). This signals a new relationship between Indigenous and Western worldviews. It is an effort to translate Indigenous knowledge for the purposes of improving the conditions of wellbeing for Indigenous people. Milo pimatisiwin is increasingly being applied to various health and wellness initiatives. The verb “seeking” often precedes “the good life.” Seeking milo pimatisiwin implies a process of understanding and regenerating Indigenous wisdom, values, ethics, and ways of life. It goes beyond the tired binary of the healthy and the unhealthy, the oppressor and the oppressed, the privileged and the marginalized.

Michael Hart (2002, 2010), of Fisher River Cree Nation, has used milo pimatisiwin as a research methodology in social work. His aim—to improve the social needs of Aboriginal Peoples—is presented by an Aboriginal helping approach. The research elaborates on five concepts foundational to achieving milo pimatisiwin: wholeness, balance, relationship, harmony, and healing. Not one of these concepts is hierarchical. Rather, these concepts further the goal of milo pimatisiwin described as “healing, learning and life in general” (Hart, 2002, p. 44).

The Chisasibi Cree Nation healing model underlines the return to the land as a way to restore community wellness (Radu et al., 2014). Radu et al. refer to *miyupimaatisiun* as their Cree concept of wellness, a way of life. Intergenerational knowledge transfer and experiential learning form the basis of this land-based initiative. Chisasibi Elders guide the program and assist participants to rethink the way they relate to themselves and others. Framed within the broader movement of cultural regeneration and Cree ways of healing and wellness, living a good life means to be “able to hunt and trap and pursue other land-based activities, that he or she has access to good food … and warmth, and is able to enjoy life and to participate actively within the community” (Radu et al., 2014, p. 95). The program situates Indigenous ways of healing and wellness as an approach to decolonizing the current models of health care.

The Sacred Relationship project, as set out in partnership with researchers and Cree Elders of Alberta, explores milo pimatisiwin further in the context of the Canadian government’s current water
policy (LaBoucane-Benson et al., 2012). LaBoucane-Benson et al. first examine colonial policies and ideologies of land ownership that have ruptured the good life. They argue for the reparation of Indigenous–Settler relations to create the good life for the benefit of all Albertans. This is done in the context of understanding the meaning of water through the knowledge of whakotowin. Indigenous Elders such as Maria Campbell shares the significance of whakotowin principles as it means to honour and to respect all relationships (Campbell, 2007).

Kim Anderson, a Cree-Métis scholar, uses the laws of whakotowin to describe the arteries of the good life. Whakotowin theoretically informs her research on life-stage cycles and Native women. She explains how “story-telling, the use of games, positive role modelling and rites of passage ceremonies” were designed to facilitate the good life in child-rearing practices (Anderson, 2011, p. 68). Rite of passage ceremonies included the values of nurturing, discipline, self-reliance, and interdependence for the entirety of one’s individual and community life. Repeatedly it is said the good life is not an individual goal. Rather it is respected as a collective and shared responsibility mediated through life cycles. This philosophy also applies to community-engaged research.

Milo pimatisiwin holds a critical role in decolonizing notions of health and wellbeing within research practices and community-centred initiatives. Many Moose Cree First Nation people have shared their concerns of how far they have moved away from ways of caring for one another, ways that were essential to a land-based survival. The practical assertion of milo pimatisiwin provides an excellent basis to break down the barriers of social isolation and to restore the Cree practices of wellbeing and values of family kinship systems, including working together to help community.

Within the context of the academy, it is important to remember that Cree knowledge intersects with the language of the people. Milo pimatisiwin is embedded in the Cree language and ways of being, doing, and thinking. For this reason, it is difficult to understand what living and being well from a Western viewpoint. Seeking to understand Indigenous thought from a Western worldview can reproduce a singular truth about health and wellbeing (Battiste & Youngblood Henderson, 2000). In collaborative projects that have accountability to various stakeholders, the larger issue is attempting to find a language that crosses both the academic and the community. It is important to avoid boxing in Cree ways of knowing using the ways that the Western world desires to categorize. It’s a dilemma to find balance but not impossible with right thinking. It remains also vital to consider the way notions of traditional and cultural knowledge differ within the community (Robbins & Dewar, 2011).

Research has demonstrated the link between paternalism and harmful effects on community wellbeing and research (Wesley-Esquimaux, 2009). Paternalistic attitudes have supplanted the ways of creating milo pimatisiwin. Such attitudes are expressed and experienced as dominant practices of one over another. Paternalism has the Latin root pater, “father.” It is devoid of Mother. Yet, as Maria Campbell reminds us, women’s role was to keep whakotowin together (Anderson, 2011). This was adult
women’s role and responsibility. Yet paternalism was and is widely practiced by governing bodies, including band councils, and Aboriginal political bodies who believe they know what is better for Indigenous Peoples. This approach has undermined Indigenous views on health and wellbeing.

Health has taken on different meanings throughout history. The Old English word *hǣlth* was associated with wholeness, prosperity, happiness, preservation, and safety. Religious doctrines understood health as a divine gift. Those who were not healthy were relegated to the works of evil. In contrast, Greek philosophers gave importance to the environment, lifestyle, and diet. This belief system influenced the way of thinking about health today. It is only in recent years that knowledge production on health and wellbeing has begun to regenerate practices that integrate historical, social, and cultural factors.

**Milo Pimatisiwin Project Context**

The Milo Pimatisiwin Project was the outcome of a broader doctoral project on Indigenous research methodologies as they connect us to land, life, and wellbeing. The community led the principal researcher (JG) to the main research question and to this very project. The relationship began with a visit to the community during which the principal researcher interviewed six youth working for a summer camp program designed by an outside organization. She also interviewed six full-time frontline youth workers and the Youth Services manager, and had numerous conversations with a broader range of community members. The intent at the time was to evaluate the externally designed youth program with an aim to strengthen recreational programming in the community. The interviews reflected interwoven themes: reliance on knowledge keepers, knowledge of the land, and reconnecting with the beauty of Cree culture. These themes guided the Milo Pimatisiwin Project and the relationship between the researcher and the community partner.

With the advent of Indian residential school systems, a community concern was in regards to loss of trust: trust in youth, Elders, Cree knowledge, one another, and the ability to be self-reliant. The Students for Canada’s North Program spearheaded by the Centre for Global and Community Engagement at the University of Ottawa provided an opportunity to collaborate on a project to strengthen culturally relevant programming at the John Delaney Youth Centre (JDYC).

In December 2013, a two-phase project was conceived—Milo Pimatisiwin: Healthy Living for Omushkego Youth. The first phase of the project was designed and implemented from January to May 2014, while the second phase took place from May to August 2015. The community identified two project objectives: (a) to foster intergenerational exchange of knowledge, and (b) to strengthen program collaboration within the community. When the first series of project funding was approved, the Youth Centre staff had changed, as did the leadership and position function. The new Youth Services Director was supportive of this initiative, given that her vision was to strengthen Cree cultural values, traditions, skills, and teachings at JDYC.
Overview of Project Phases and Activities

In the first phase, the JDYC sought to centralize pimatisiwin knowledge within their programming infrastructure. The aim was to bridge the intergenerational learning gap by bringing together various stakeholders in youth programming. This led to the development of the first culturally based youth camp in addition to the first series of online pimatisiwin teachings. The teachings were transmitted over the local radio station situated in the JDYC. Two community youth were hired to work on the project.

The second phase of this project built on these first initiatives. The intent was to enhance the project sustainability and capacity-building within JDYC. The project focused on a community-based evaluation to engage the community in expressing their needs, roles, and vision for youth wellbeing. The principles of the Northern Cree metaphor of the Canoe Trip for conducting research were applied to develop a community evaluation process (Michell, 2012). In addition, land-based initiatives such as traditional walking out ceremonies, youth-centred sweat lodge ceremonies, and fishing trips were part of the project activities.

Land-based initiatives included teaching youth how to fish: how to set a net, use a fishing rod, and clean and prepare the fish for cooking. The youth were linked with Elders and individuals with significant traditional land knowledge. Youth were also given the experience of learning the basics of moose hunting. Youth gained basic knowledge of gathering and preparing Cree traditional food but also the values that were originally taught. This included making an offering for the animals to give thanks for what the land provided, as well as the social aspect of connecting with others and especially Elders, the original teachers of Cree youth and children.

For Cree people, the land, language, family/community relationships, and spirituality are interwoven and not segregated as in Western beliefs. It was expressed that a spiritual connection is gained when Cree people return to the land. This can be hard for individuals to comprehend when connection to the land has been severed. The land provided everything needed to live well. To reconnect provided not just physical nourishment from the food harvested but also nourished the mental, emotional, and spiritual aspects of life.

Methodology

Participatory, reciprocal, experiential, and relational values played a significant role in the project and research approach (Absolon, 2011; Gaudet, 2014; Kovach, 2009, 2010; Michell, 2012). An Indigenous methodology centres on coming to know through relations, cultural knowledge, and social context. These efforts are not isolated from one another as they are rooted in an Indigenous worldview. Reclaiming a place-based and language-based understanding of health and wellbeing informed the approach to community and youth engagement, the data gathering process, and meaning making from the voices of project participants themselves.
Given the reporting requirements to the funders, the JDYC prepared attendance forms to track number of participants. The numbers indicated that 97 community members participated in the project activities that were promoted through the JDYC Facebook page, posters at the JDYC, visiting, and various community forums. The four youth hired to be part of the project were recruited through the JDYC and word of mouth, and some were directly invited by community leaders given their experience and knowledge in previous land-based initiatives. The indirect beneficiaries were the unknown number of community members that listened to the pimatisiwin teachings over the radio. The four community youth hired in the project were mentored in weekly verbal check-ins and exchanges through visiting. They completed a final project reflexive journal that expressed what being part of the project meant to them, what they felt they learned, what challenges they experienced, and what recommendations they had to improve future projects.

Meaning making within Indigenous inquiry (interpreting the youth stories) was congruent with an Indigenous research methodology grounded in the understanding that knowledge is relational and learning is experiential (Chilisa, 2012; Kovach, 2009). The analytic lens was holistic given the project aim was to foster and to reclaim the pimatisiwin way of life, to explore lessons learned and community strengths with this community-based initiative. This holistic approach informed the theme of learning with and from the youth and the design of the project along with lessons learned. It further enabled us to situate the youth’s input, their experiences, and their concerns and to grow the project vision of healthy living by visiting and learning from one another. Learning by doing is also a method embedded in an Indigenous worldview (Absolon, 2011). The way of visiting is a well-known Métis and Cree way of taking care of our relations and pimatisiwin. We met frequently and discussed our shared learnings and worked closely to ensure the validity of the analysis process, promoting a reflexive dialogue.

The Milo Pimatisiwin initiative supported the JDYC’s interests and concerns. Re-centring research to address community concerns and knowledge is central to decolonizing methodologies (Smith, 2012). Building on existing programming in the community, the Milo Pimatisiwin team engaged four community youth workers, the radio DJ producer, four Moose Cree knowledge keepers, the Youth Services Director, the Project George coordinator, and a University of Ottawa student/researcher. For the duration of the project, the project coordinators, the Youth Services Director, and the principal researcher dialogued with the Centre for Community and Global Engagement and Associate Executive, Moose Cree First Nation Band, to implement the project objectives and oversee activities, reporting, and results. A conversational method ensured that voices were respected and heard (Kovach, 2010). This resulted in fluidity, transparency, and trust and the co-creation of this study. The evaluation of the study was consistent throughout the project. In addition, a formal project report was completed for the stakeholders.

Several different knowledge-gathering methods were applied to ensure mutually benefiting outcomes for all parties involved (Chilisa, 2012; Kovach, 2009, 2010; Wilson, 2008). Visiting,
conversations, observation, and experiential learning were methods applied to track the process, results, feedback, and lessons learned. The ethics specific to the knowledge transmission of pimatisiwin teachings were determined by Chris Hunter, Cree Language Educator, responsible for this portion of the project. Again, re-centring ethics to cultural context and protocol is an integral approach to legitimize Indigenous research (Smith, 2012). Academic ethical requirements were also met through obtaining verbal and written consent from participants.

**Pimatisiwin Teachings Protocol**

One of the first steps to be respected when working within an Indigenous context is cultural protocol (Hart 2010; LaBoucane-Benson et al., 2012). Cultural values should inform the approach of the research and project collaboration. A relational way of being, learning, and doing requires an accountability and responsibility to the knowledge keepers, those who carry the knowledge. Respect for cultural protocols ensures that knowledge is treated in a good way and used in a good way.

> *It is the act of showing respect ... it is the acknowledgement that learning occurs in the context of relationship ... it is the acknowledgement of the time and effort the teacher has dedicated in the pursuit of knowledge. Observing this protocol, therefore, affirms commitment to—and enhances—the learning process.* (LaBoucane-Benson et al., 2012, p. 2).

Cultural protocol within both research- and community-centred projects goes beyond the academic ethical requirements of signing consent forms. Within the context of this project, it was important for Chris Hunter to ensure that he received family blessings to pass on his late grandfather John Joseph Chookomolin’s teachings before proceeding. Chris explained that he would not have participated in this project of sharing the teachings online or archiving the teachings if he had not received this blessing from his mother. We are grateful to Chris and his family for reminding us of the importance of respecting protocol and the lineage of teachers, and for their lifelong dedication in protecting this knowledge. In reflecting on the results of the project, Chris shared his experience:

> *My overall experience has given me the opportunity to pass on Mino Pimatisiwin Teachings to the next generation. It made me appreciate the Indigenous teachings of the Cree People, which these teachings has withstood time since time immemorial and has survived to modern era. Bringing back old teachings of the Cree People into the modern era made me proud of who I am. I really appreciate this experience, I always wanted to document, record, and share our Cree teachings that our Elders safe guarded. I honestly believe that in the generations to come after I pass on to the spirit world that our way of Mino Pimatisiwin will be well known, documented, and passed on, for I believe it is in good hands.* (Personal communication, n.a.).
Some of the challenges to gathering knowledge were the time frame, and the ability to capture stories from Elders in other remote communities who still live in accordance to the pimatisiwin teachings. Given that many Elders are not plugged into modern technology, the only way to receive the knowledge of Elders is to go to them and visit. Visiting is an Indigenous way of life and a viable methodology of coming to knowledge. This was not possible within the time frame and limited resources available for travel.

Results: Milo Pimatisiwin Project Deliverables and Challenges

In order to gain trust, we have to give youth knowledge. Knowledge of how to travel on the river, hunting on the land, in the winter and not placing ourselves in harm’s way. (D. Dick, Moose Cree community mentor, personal communication, June 2, 2014).

We recognize that the project objectives were lofty, yet much was accomplished with care and consideration of what could realistically be achieved. Both phases of the project involved learning from and with the land. The initiatives were diverse: cultural camps, community feasts, pimatisiwin teachings, and traditional rituals such as the walking out ceremony and youth sweat lodges.

Moose Cree Cultural Camps

The cultural camp activities were typically fishing day trips, trapping and setting rabbit snares, and going out on the land. The purpose was to expose youth to the Cree way of life, land-based ways of learning, and Cree knowledge. The objective—to increase collaborative efforts between other programs—was to nurture capacity from within the community. Silos of information were a constant, ongoing challenge, and bringing together a few service providers was a positive start. The cultural camp component of the project served as a template for future cultural camps. Between Phase 1 and 2, a full-time Cultural and Language program coordinator was hired at the JDYC. This position fostered program collaborations and as such resulted in Fish Week, Spring Hunt Week, and Moose Week.

Modernizing Pimatisiwin Teachings

Another significant component of the project was to record and to broadcast seven modules of pimatisiwin teachings over Youth Island Radio 107.1. These remain part of the radio station’s archives and the JDYC. The archives established a cultural foundation and learning tool for generations to come. The radio allowed people to learn anonymously given there is still a fear/distrust of milo pimatisiwin knowledge. The method of teaching through modern technology provided listeners with anonymity and the private space to restore trust in Cree knowledge. With the impact of residential schools, people were taught not to trust themselves; the pimatisiwin way of life was shamed (Gaudet & Martin, 2017). Community members feel that land-based learning has to happen more quickly, yet it is a lifelong process that involves all generations, and Cree knowledge keepers are decreasing in numbers with every
Given the positive feedback from the pimatisiwin live streaming, the project sought to build on the capacity by increasing the accessibility of the communities’ stories of the land. Pimatisiwin teachings were elaborated and translated in Cree for further sharing on the community app. This component was developed in unison with another JDYC project. The community app allowed youth the opportunity to learn about and to listen to Cree cultural teachings through modern technology.

**Youth and Community Engagement**

A third project deliverable was to engage community youth to work on the project. The purpose was to create sustainability within the community by providing youth with an opportunity to nurture their gifts and strengths. Some of the challenges for hiring community youth were related to administrative issues, criminal record checks, and conflict of interest, as well as scheduling. Despite these challenges, four community youth—largely young adults—were hired. They provided important perspectives on their experience and valuable insights on ways to strengthen JDYC initiatives.

**Learning from and with the youth.** The youth helpers felt they learned new skills and strengthened their own skill sets. They felt they were able to connect with the youth, given the similarities of their respective struggles. The Milo Pimatisiwin youth helpers could empathize with the boredom, the isolation, and the lack of guidance for healthy living.

> It was a growing experience too especially working with youth. Before I wasn’t really good with younger people in terms of talking to them, it helped me to grow personally and to explain and to talk to them in a way that they’d understand. The youth seemed bored at times and we would encourage them. Be more like a friend than an authoritative level. (Milo Pimatisiwin cultural camp helper).

> Training with Project George actually made myself more confident, comfortable and also gained new knowledge of the outdoors then I have recently possessed within myself. (Milo Pimatisiwin cultural camp helper).

One youth helper was concerned with the lack of positive role models in the community and the normalized behaviour of the use of drugs and alcohol. She felt the lack of support and coping mechanisms made it difficult for youth to make different life choices. Two youth helpers were concerned with the lack of planning on the part of the JDYC. Given the project’s significance in providing emotional and spiritual support, they felt it was important that more youth and parents be

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1 Visit http://moosefactorystories.com

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better informed of the projects.

_I believe the project would become more successful and known if we would accept a wide-range of youth of different ages and even parents to join us on our expeditions and activities around the community. (Milo Pimatisiwin Project George camp helper)._

Activities could have been planned out more ahead of time and lack of communication in terms of location of events made it difficult. It worked out in the end. I think in the future planning stages need to be strengthened. (Milo Pimatisiwin cultural camp helper).

One youth helper expressed concern that the regulations on boat safety and licensing would replace the value of knowledge keepers who grew up on the river. He felt more reassured travelling with and learning from the old men than from someone who just got a boat license. He further emphasized that he’d trust them more than himself:

_Some of the challenges are that some of our most experienced men on the river don’t have a boating license but now apparently, there is need to have a boating license. The ones who have been doing this for years, their whole life, can avoid any dangerous incident and accident than someone like me who just got a license. I hope they think about this. (Milo Pimatisiwin cultural camp helper)._ 

The voice of youth knowledge brought an awareness of the potential for new boat drivers to learn from the Elders. This would result in another means of fostering intergenerational learning. Book knowledge from the south may not necessarily apply to this remote region. We discussed with the youth the possibility of designing a Moose Cree version of boat safety, and in fact, this is how they prefer to learn. This built on the importance of practical hands-on learning as emphasized by the youth:

_Practical hands on approach to learning basic skills is important to get a feel for it. Even basics, like making a fire are important. When you go out to the land with some knowledge, you begin to see what the medicines, what the tools are, what is needed, what is out there. This is important because not much people are knowledgeable about culture and land and just see the surface. I feel people need to be taught more about and do not get much exposure to that kind of cultural activities. I hope exposure brings deeper respect for our culture. It feels like it is slowly dying … it just feels like it is really important for people to learn the basics of being in the bush, and how to do certain things_
to build a foundation for the youth to build on. Expose it to them and see if they like it. (Milo Pimatisiwin cultural camp helper).

Each Milo Pimatisiwin Project helper brought valuable insights, concerns, and recommendations on how to continue to invest in and to improve land-based initiatives. They expressed the ongoing challenge of engaging youth and providing them with opportunities for land-based learning, given the influence of drugs and alcohol in the community. Many of the youth have expressed repeatedly they want to learn and have access to these events, yet turnout can still remain low for some events while others can surpass expectation. Within the community many of the youth feel they are unimportant, or what they would like to see made available is ignored or dismissed by leadership.

The impacts of colonialism inclusive of residential schools are still present. Traditionally the children and youth were at the centre of communities and families. Around the children and youth were the Elders, their teachers and guardians, then the women surrounded them, and then men protected them all. With the multigenerational impacts of colonialism, the removal of the children and youth has altered the learning system and values within communities. Children and youth feel this, live this, and start to believe this. The struggle to shift and return these values is an ongoing challenge. The Youth Services Director seeks to find the balance between providing the activities for youth and ensuring that they are safe when they participate in these initiatives. Finding the balance between Cree traditions and modern-day requirements, laws, and practices is a challenging reality and responsibility.

Cree-specific evaluation tool. In Phase 2, we produced a Cree-specific assessment tool to assist the JDYC in evaluating its own successes and strengths. This was a direct result of the challenges in the first phase of the project as a means to counter the notions of success from a Western-based funder’s perspective. The purpose was to reflect the community’s indicators of success, in addition to a process whereby Cree values and priorities informed and guided their respective evaluations (Michell, 2012). From this tool, a community-based survey was implemented to provide clarity on ways to strengthen the vision of Youth Services and to grow the use of the community radio station.

Vision of Youth Services Director, John Delaney Youth Centre

The JDYC morphed into what it is today over many years. It was originally constructed to be a business/entrepreneurship centre. It has become a designated space for youth. Originally there were only two staff members that provided drop-in and gym activities for youth. It grew and other team members joined, providing various programs and services for youth. As of 2015 there is a staff of nine with a variety of programs, gym activities, dances, special events, and the newly added Culture and Language worker/program plus the community radio station.

The JDYC has created a space where youth can liberate themselves, even briefly, from home challenges. Given that youth are assuming a lot more familial responsibility at early ages, children have
to be adults earlier. This has disrupted the cycle of pimatisiwin. For this reason, life-stage teachings and ceremonies are emerging out of the JDYC as opposed to within a traditional familial setting. The director is seeking to re-instill the cycle of life teachings that taught how to be a good and loving human and how to fit in the world around them. The Milo Pimatisiwin Project has helped to reintroduce this knowledge within this public and community-based setting.

The director believes that in order to reverse the effects of residential schools and colonialism, it is important to make the knowledge and Cree traditions available to the youth. Mainstream school does not provide these opportunities. With the effects of colonization much of this knowledge exists in a gulf. It is a challenge when people do not know where to access the knowledge. A prime example of this took place during the second phase of the project.

Creating Safe Space

The JDYC worked with traditional knowledge keepers and gave young parents the possibility of having a Walking Out Ceremony for their babies. As the pimatisiwin teachings were traditionally practised in the Cree culture, each stage of life and development was marked with rites of passage. The Walking Out Ceremony is one of the first ceremonies for our people as they grow and develop as human beings. The ceremony is normally done when babies are 1 year old. In this ceremony they are introduced to the world (physical and spiritual), and the community honours the little ones’ first year of life plus their parents. It is a celebration of each young person’s life, their parents, grandparents, other family members, and friends gather. Everyone acknowledges that child and expresses what they wish for that child as the child grows. A commitment is made to support the child through their next stage of life. The ceremony also acknowledges the hard work parents and grandparents do for that child to help them grow. The Walking Out Ceremony that the JDYC assisted with gave many young parents the possibility to offer this for their babies. Six babies had this rite of passage, with their parents and family members present; over 50 people were in attendance that morning. The young parents had expressed they wanted this done for their children and knew it was important but did not understand why. They did not know what they needed to do and all that was involved. The JDYC was able to assist them and bridge that gap.

The Moose Cree community is fortunate that it has a good core of people that have retained the Cree knowledge, knowledge that was forced into hiding due to our land-based practices being outlawed by the federal Indian Act. The mistrust of traditional Cree practices was ingrained into the older generations, and the younger ones and youth know that something is missing. They are starving for the knowledge that is an inherent right. Introducing them to their culture and strengthening their identity can help remedy the social problems that exist.

Filling Our Cree Cup

The Youth Services Director applies the analogy of a cup. Prior to contact, our Cree people had
our own cup. It was filled with our traditional practices, connection to the land, spirituality, language, family roles and responsibilities—our Cree ways. The occidental systems that were enforced emptied that cup; they allowed for the negative effects to enter and become normalized. This is the violence, alcohol, drugs, poor health choices, disconnection from the land and our traditional food (the practices of gathering and preparing). All of this compounds itself and manifests in the numerous social problems that exist: poor health conditions, poverty, difficulties with the justice system (disproportionately high incarceration and crime rates), violence against women and children. Our cup has been filled with too many things that do not serve us but rather harm us. Refilling our cup with what was stripped and taken is invaluable to our holistic wellbeing and will provide our youth and people with the core, the solid foundation to being a Cree person in the world today.

Youth have the unique circumstance where they must learn who they are as a Cree person to fit in the contemporary or Western world. Our youth and our people would benefit greatly from learning to walk in both worlds. They need to understand how their life circumstances came to be, that the social conditions that exist are the effects of the “-isms”: colonialism, racism, sexism.

In order for this knowledge to be shared and to counter the negative impacts of colonization, we must make this information accessible in new formats. We must preserve what is quickly being lost, share this information, and learn to trust what our Cree ancestors lived by since time immemorial. Many of our traditional ways have been altered with the use of modern or Western tools. For example, hunting with guns, getting on the land with snowmobiles, motorboats, helicopters, trucks. The values and importance of the activities remain present with the added benefit of the new tools. Sharing the traditional knowledge with tools like the internet, apps, and the radio station can make it accessible to our youth, who are learning to use technology at a rate unprecedented in our history, as well as making it accessible to a broader audience. Given that much of our Cree population has migrated, like the majority of Aboriginal people in Canada, to urban areas, making this knowledge and these values easily accessible is important.

The Youth Services Director has worked in a variety of areas, seeing and experiencing the impacts of the loss of culture, identity, and connection to the land. The traditional Cree values that were once universally understood recognized the importance of instilling pimatisiwin teachings in our people—to prepare them, strengthen them, and ensure that our children are equipped to be strong, healthy Cree beings. Normalizing these traditional practices and sharing the pimatisiwin teachings are vital to the survival of our Cree identity. We must ensure that they are accessible for all who want to learn, to heal, and to grow as human beings. Doing so will help them “fill their cup” and develop an understanding of the current social context they live in. The current social conditions that exist for Aboriginal people today took many years to manifest, since contact and even before the creation of the Indian Act and residential schools.
The pimatisiwin teachings were once organic and practised daily. To have them brought back will take many years. It is important to start today, and with the children and youth. One traditional healer stated Cree people would use ceremonies and other practises to celebrate, honour, and give thanks for life and seek guidance. Today they are used to heal, hopefully, so that in our future our children and those yet to come will not need to heal for what has been lost.

**Discussion: Milo Pimatisiwin Project Lessons Learned**

*I re-learned the importance of a helper’s role. I did not come into the community with answers to questions. They have their own answers, solutions and clear vision of how to create healthy living for their youth, families and community in general. I remembered the importance of unlearning in order to listen and to act from within. When there is equal accountability to the life within and outside, there is trust. (University of Ottawa doctoral student).*

The concept of milo pimatisiwin weaves a theoretical, epistemological, and methodological approach to inform youth programming, community leadership, and engaged research. Long-term vision, Elder and youth engagement, knowledge keepers, resources, and commitment are required elements to re-create milo pimatisiwin in a modern context. The collaboration between various stakeholders is critical to the construction of an alternative conception of health and wellbeing along with implications for land-based initiatives. We have captured the following lessons learned in three themes. These lessons could inform potential best practices, guiding principles, and/or policy development.

**Outsider–Insider Relationships**

Within the context of this project, it was important for the authors not only to facilitate the project but also to live the pimatisiwin teachings. Doing so helped us to understand and to confront our responsibility to address the inadequate system that First Nation, Métis, and Inuit communities must work with and exist in. It was important to support one another in maintaining an appreciative attitude, taking care of ourselves, and not succumbing to deficit thinking given the challenges.

For outsiders coming into the community, it is important to take time to learn from and with the community. To grasp and to empathize with the concerns regarding current social conditions is not easy. It is important to have one’s own wellbeing bundle and to seek support from the community and Elders. This support fosters a deeper sense of cooperation and sense of community spirit. Cultivating the teachings acquired through experience can uplift one’s consciousness. This is vital in researcher–community engagement if we are to remain focused on a shared vision for the future.

Consistent three-way communication between the Moose Cree First Nation band council, Centre
for Global and Community Engagement, and the University of Ottawa student ensured a mutual influence on each other and shifted power differentials. With this type of attitude and approach, there is room for “outsiders” to assist in supporting the interests of community given the loss of trust from within the community. An outsider can be heard differently, as the associate director explained to the group. It is, however, important for the outsider, in this case a Métis researcher from another community, to be grounded in her own history, identity, and values. This knowing helped to respect the difference in Cree values and ways of being. Critical self-reflexivity is vital to maintain a balance of being a helper and being accountable to academic timelines and project deliverables.

Land-Based Health

Indigenous thought on health and wellbeing disrupts the Western paternalistic ideologies of health and wellbeing. Health is not separate from one’s identity; therefore it does not fit within an ideology of individual responsibility separate from community. Indigenous Peoples’ worldview on health goes further. Health and wellbeing have to do with the balance of relationships with land, identity, and family (Adelson, 2000; Anderson, 2011). Cree thought and consciousness offers a renewed outlook of wellbeing for a diverse generation. Through our shared experience, we further suggest that milo pimatisiwin principles served to ground a collaborative research project and initiative from the bottoms of our feet.

Just as there is not only one way to spell milo pimatisiwin, neither is there only one way to live the good life. It was important in this process not to become dogmatic about what living and being well means. It is a living concept in relationship with Spirit that ebbs and flows with the seasons of life, experiences, and environment. There is rhythm within nature that cannot always be followed with a schedule and clock. In other words, being flexible and gentle is important. The means to achieving the good life may be altered with time and technology, but the values learned and practised remain the same.

Elder and Youth Engagement

Reliance on Elders’ wisdom, skills, and stories in land-based initiatives is essential to also restore the value of their role and responsibility to community wellbeing and research initiatives (Gaudet, 2014). As one youth leader said, “To involve our Elders is how to bring change.” There also needs to be an understanding that elders are not necessarily Elders when they achieve a certain age. Some of the communities’ Cree knowledge keepers are young and possess a considerable amount of knowledge. Understanding that knowledge can come from everyone, including our youth and children, was one of our greatest teachings.
Reconnecting youth and Elders provides mutual benefits to each demographic. During the project there were many Elders that expressed how they enjoyed teaching the youth, and longed for more opportunities. These interactions provided both Elders and youth with a sense of belonging and purpose. The JDYC observed changes in attitudes for some “problem youth” after they spent several days on the land and water, and learning from the Elders. The youth received guidance, praise, gentle teasing, and humour to create learning opportunities. It is important to consider what the Elders need to be well, and the protocol required to engage their services in constructed land-based initiatives.

Conclusion

This project has provided stepping stones to integrate local resources and land-based knowledge in community initiatives and in the growing field of Indigenous research practices. Both were guided by the ways of the land, context, and knowledge of the people who have learned and lived with the land, as well as people who are learning. The approach intersects hands-on experiential and practical learning, teachings about life, and living in two worlds. We sought to weave several components: emotional, spiritual, physical, and social. The project nurtured the foundations of cultural regeneration within the infrastructure of JDYC. It included many generations, all important for youth wellbeing.

The project disrupted the siloed operation that is not unique to First Nations people but that is driven by a logic that can make it difficult to apply the teachings, given the limited resources and accessibility of youth and Elders. The study challenged knowledge production from an outsider’s gaze and created awareness-based Cree ways of seeing and learning from the knowledge that flows from a connection to the land. The re-centring of land-based knowledge at the JDYC offered a springboard from which to share and to retell intergenerational stories through modern technology, inclusive of academic institutions.

The Omushkego people, like many Indigenous communities, are coming out of a long history of exploitative impositions and paternalistic attitudes (Brokenleg, 2012; Wesley-Esquimaux, 2009). There is a continued fear and apprehension about activities that are culturally relevant. This project has assisted with legitimizing the importance of the work that must come from within the communities themselves. The Moose Cree community has for decades been seeking to address the damages resulting from attempts to break down Cree culture. The Milo Pimatisiwin Project is one of many collaborative initiatives designed to strengthen human relationship, connection to the land, and continuity of cultural practices, values, and skills.

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Master in Public Health in Indigenous Health

In this field, Indigenous health issues will be examined from multiple perspectives and world-views. Indigenous knowledges, pedagogies, and approaches to research will be utilized in tandem with Western approaches. Opportunities for land-based learning, traditional medicine teachings, interaction with Elders, and community engagement will permeate the program. Students will gain a broad public health knowledge base with specific expertise in Indigenous health issues.

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Understanding the Sleep Habits of Children Within an Indigenous Community.

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Understanding the Sleep Habits of Children Within an Indigenous Community.

Abstract
This study was developed within the participatory research framework of a diabetes prevention project to understand the meaning of sleep and sleep habits of Indigenous preschool and elementary school children. Sleep deprivation is a known risk factor for obesity and Type 2 diabetes. A philosophical hermeneutic approach utilized interviews and focus groups with cultural knowledge holders, Elders, parents, teachers, and school administrators. The findings reflect how Indigenous community members understood sleep through the themes of traditional ways, changing times and concerns, increasing technology, generation gaps, parental responsibility, eating habits, physical activity, and children’s behaviours in school. After dissemination to the community, the findings were combined with traditional teachings and national recommendations to develop culture- and age-appropriate sleep-promoting educational materials for schools and the broader community.

Keywords
Philosophical hermeneutics, sleep habits, children, Indigenous health, school health, community-based participatory research, community.

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Conflict of Interest
This was not an industry-supported study. The authors declare no conflict of interest.

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Introduction

It’s easy. Dr. Martin Luther King said it . . . I have a dream . . . and we want you to have your own dream. Every night around ten o’clock. (Parent participant).

The objectives of this research project, undertaken by a community-based participatory research team with both Indigenous and non-Indigenous members, were (a) to gain an in-depth understanding of how sleep was interpreted within an Indigenous context, culture, and worldview, and (b) to gain information about the sleeping habits of children in the Kanien’kehà:ka (Mohawk) community of Kahnawà:ke, Quebec, Canada. Our intent was to combine findings from this research, community traditional knowledge, and evidence to develop culture- and age-appropriate educational materials to inform and promote healthy sleeping habits and well-being for preschool and elementary school children and their extended families.

Kahnawà:ke is part of the Mohawk Nation and the Iroquois or Haudenosaunee Confederacy, with a traditional food system based on agriculture, gathering, hunting game, and fishing that has greatly diminished in recent decades due to increasing urbanization. Today Kahnawà:ke has a population of 7,859 people (Aboriginal Affairs and Northern Development Canada, 2015). It is situated 15 km south of Montreal and lies in close proximity to other, non-Indigenous communities. Kahnawà:ke has a long history of independence and autonomy, with current control of many services including health, social services, and education (Bisset, Cargo, Delormier, Macaulay, & Potvin, 2004). It also has high levels of education and employment, including many of the staff in community-controlled organizations. In 1985, and again in 2007, the prevalence of Type 2 diabetes was documented as twice as high as the Canadian rate (Horn et al., 2007; Montour & Macaulay, 1985), although much lower than many other Indigenous communities where rates of Type 2 diabetes are 2–5 times the national rates (Young, Reading, Elias, & O’Neil, 2000).

When the initial high prevalence of diabetes was first documented and results were shared with the community in the late 1980s, community Elders asked that “something be done” to address these high rates of disease and furthermore that efforts should focus on young children. Following this request a team from the community-controlled organizations of the hospital, social services, and the Kahnawake Education Center invited academic researchers to join the effort for their expertise in health promotion and evaluation (Macaulay et al., 2006). The resulting Kahnawake Schools Diabetes Prevention Project (KSDPP) was developed in 1994 to decrease the onset of Type 2 diabetes among present and future generations. The main objectives are to increase daily physical activity and healthy eating habits among Kahnawake children. Other important objectives are to mobilize the community, to foster community empowerment and ownership through participation in all aspects of the project and to build capacity within Kahnawake to ensure sustainability of KSDPP goals, objectives and activities in the future. (KSDPP, n.d.-a, para. 6)
The KSDPP community-based participatory research partnership includes the research team with Indigenous and non-Indigenous researchers and the KSDPP Community Advisory Board (CAB). CAB is a coalition of volunteers from several different public service organizations within the education, recreation, health, culture, and political sectors, along with interested individuals who care about the prevention of diabetes (KSDPP, n.d.-c). University and community members work closely together guided by the KSDPP Code of Research Ethics that was jointly developed by community and university members in 1996, when development was led by an academic researcher, and in 2007, when the revisions were led by a community researcher. The KSDPP Code of Research Ethics outlines the obligations of the community and university members and guides the full team throughout all phases of the research from finalizing the research questions, deciding on data collection methods, and collecting data to interpreting preliminary findings and disseminating the results (KSDPP, 2007). Within KSDPP a Two-Eyed Seeing approach became the relational process that the researchers, both Indigenous and non-Indigenous, evolved and adopted over several years as researchers and community members learned to effectively and respectfully work together. The concept of Two-Eyed Seeing was originally developed by Mik’maw Elder Albert Marshall (Bartlett, Marshall, Marshall, & Iwama, 2015) as a means of integrating both Indigenous and Western experiences, philosophies, and ways of knowing to promote positive relationships among researchers. It is recommended by the Institute of Indigenous Peoples’ Health at the Canadian Institutes of Health Research (CIHR, 2014) and by the Institute for Integrative Science and Health (n.d.). Two-Eyed Seeing is a complex relational interaction among people who are ontologically, culturally, historically, and philosophically different but linked by their willingness to engage in a relational process toward a common horizon of understanding. A detailed description of how this process has unfolded in KSDPP can be found in an earlier KSDPP paper (Hovey, Delormier, McComber, Lévesque, & Martin, 2017).

The vision statement of KSDPP, developed at the beginning of the project, states:

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is committed to prevent type 2 diabetes in Kahnawake. We empower community members to care for their personal and family health through continual improvement of our unique diabetes prevention model based on Kanien’kehà:ka values. We collaborate with all community organizations on a shared vision of diabetes prevention activities that reach all community members. The project continues to develop our research model based on the experiences of Kahnawakero:non, staff and researchers in a partnership between Kahnawake and universities. It is shared with other Aboriginal communities and all others involved with diabetes prevention. KSDPP trains a significant number of Aboriginal people in diabetes prevention intervention and research activities. (KSDPP, n.d.-b).
To date, numerous KSDPP school and supporting community-wide interventions have helped to increase knowledge about healthy lifestyles. The interventions include organized culturally relevant school and community events, as well as a culturally appropriate health curriculum for elementary schools delivered by teachers and developed by staff from the community hospital, KSDPP, and the elementary schools (Delormier et al., 2003; Macaulay et al., 1997). Many of these efforts include the promotion of traditional foods (Murdoch-Flowers et al., 2017). Community ecological changes, such as only healthy foods at the youth centre and a new walking path, provide increased opportunities for children and their families to eat healthily and be physically active. In partnership with the community elementary schools, KSDPP has also helped to develop school-based wellness policies promoting healthy eating and increased physical activity (Hogan et al., 2014; Macridis et al., 2016). All these endeavours contribute to building knowledge, skills, and capacity and promoting empowerment, wellness, and ownership (Cargo, Delormier, Lévesque, McComber, & Macauley, 2011; Salsberg, Macridis, Garcia Bengoechea, Macaulay, & Moore, 2017) as recommended by the Truth and Reconciliation Commission of Canada (2015) and the UN Declaration on the Rights of Indigenous Peoples (United Nations, 2008).

Why Sleep Matters

Recent evidence demonstrates that both adults and children with shortened sleep are at increased risk of developing obesity (Chaput et al., 2011; Chaput & Tremblay, 2012; Taveras, Gillman, Pena, Redline, & Rifas-Shiman, 2014), which is a major risk factor for developing diabetes. In a project with children aged 5–10 years, it was shown from parental reported questionnaires that shortened sleep was the most important risk factor for being overweight and obese when compared to other contributing factors such as parental obesity, greater than three hours of television viewing, and physical inactivity (Chaput, Brunet, & Tremblay, 2006). A meta-analysis of 11 longitudinal studies, comprising 24,821 participants, revealed that subjects sleeping for short duration had twice the risk of being overweight or obese, compared with subjects sleeping for long duration (Fatima, Doi, & Mamun, 2015). In adults shortened sleep is also an independent risk factor for developing Type 2 diabetes (McNeil, Doucet, & Chaput, 2013; Reutrakul & Van Cauter, 2014).

Risk factors for shortened sleep in children include presence and use of electronic media in their bedrooms (Cespedes et al., 2014; Chahal, Fung, Kuhle, & Veugelers, 2013). One study found that having a bedroom television is associated with weight gain beyond the effect of television viewing time, a finding that “could be the result of uncaptured effects of television viewing or of disrupted sleep patterns” (Gilbert-Diamond, Li, Adachi-Mejia, McClure, & Sargent, 2014). Another cause of shortened sleep in children is excess daytime caffeine intake (Calamaro, Yang, Ratcliffe, & Chasens, 2012; Warzak, Evans, Floress, Gross, & Stoolman, 2011).
Methodology

Study Design

Because of the above evidence linking sleep deprivation with increased obesity in children, and obesity and Type 2 diabetes in adults, KSDPP researchers and CAB members together decided that KSDPP should consider promoting healthy sleeping habits in addition to their long-standing promotion of healthy eating and increased physical activity. The overall KSDPP team also decided that it was important to first ask community members about their insights into sleep and to evaluate the actual sleep habits of both preschool and elementary school children. This background information was especially important as we could find only one other article from Canada evaluating the impact of electronic media on sleep duration for Indigenous youth ages 10–15 (Gates, Hanning, Martin, Gates, & Tsuji, 2013) and none about sleeping habits of young Indigenous children. Our main goal was to use the findings from this study to contribute to the development of culturally appropriate sleep-promoting materials and new interventions for community members, school staff, and young schoolchildren. This idea was then discussed with the Kahnawake Education Center, Elders, and principals and teachers of the preschool and elementary schools, who were all supportive of the proposal.

In 2012, with this community support, the community–academic KSDPP team wrote a successful research grant proposal to undertake a study that consisted of two phases. Phase 1 consisted of gathering information from community Elders, cultural knowledge holders, parents, teachers, and school administrators about how sleep was interpreted within an Indigenous context, culture, and worldview. Phase 2 consisted of a descriptive quantitative examination of the actual sleep and sleep hygiene of young children at five Kahnawà:ke schools (Seganathy, 2014). The research questions were as follows:

1. How is sleep understood from an Indigenous perspective?
2. What are the actual sleep habits and sleep hygiene practices (e.g., use of electronic media in children’s bedrooms and use of caffeine) of preschool and elementary school children in this community?

This paper offers the findings from Phase 1 with some additional results from Phase 2.

Phase 1 of this research project was guided by the philosophical hermeneutics of Hans-Georg Gadamer (Gadamer, 1989). Philosophical hermeneutic inquiry is described as the practice and theory of interpretation and understanding in human contexts and has been shown to have invaluable applied utility that has been well documented within healthcare research (Hovey et. al., 2017; Moules, McCaffrey, Field, & Laing, 2015). It involves an exploration into human experience (Davey, 2006; Gadamer, 1989), and philosophical hermeneutic researchers’ intentions are to gain insight and understanding through the ways in which individual participants, as well as participants as a collective, make sense of their experiences with regard to a shared topic (Hovey, Delormier, & McComber, 2014). Self-reflection, including recognizing and acknowledging one’s assumptions and biases with a thorough
understanding, and consistent application of the philosophy make up the rigorous elements in philosophical hermeneutic data analysis. Interviewing, transcribing, listening to audio recordings, and grouping similar interview excerpts familiarize the researchers with the data and facilitate the development of “findings” that address the research question (Moules et al., 2015).

**Participant Recruitment**

Ethics approval was obtained from the Kahnawà:ke Schools Combined Schools Committee (the governing body representing the schools), the school principals, the KSDPP’s CAB, and McGill University’s Faculty of Medicine Institutional Review Board. In Kahnawà:ke, the CAB oversees and guides all KSDPP activities, including research. Under the guidance of the KSDPP Code of Research Ethics, one of CAB’s goals is to ensure that cultural and community values are upheld and protected through partnering in all grant applications, reviewing all data collection tools, interpreting preliminary results, and disseminating the findings (KSDPP, 2007).

The Indigenous research coordinator (AP), who lives in the community, first approached KSDPP staff and CAB members to develop a list of community Elders and cultural knowledge holders who might consent to be individually interviewed to get their perspectives and understanding about children’s sleep habits. These Elders and cultural knowledge holders were from the Cultural Centre and the Longhouse whose occupations and knowledge about Haudenosaunee (People of the Longhouse) culture allowed them to comment on sleep and the importance of mythology and dreams. In accordance with CAB’s mandate, it was important to begin with these Elders and cultural knowledge holders to ensure the research proceeded in a respectful, culturally appropriate manner. Eight interviews were conducted in total.

The research coordinator then approached school administrators, teachers, and parents from the four community elementary schools and the preschool, during one of the parents’ days that occur two times per year. The research project was explained and invitations offered for participation in focus groups centred on how children sleep at home and its potential effect during school time on behaviour and attention. Three focus groups each consisting of between 7 and 9 participants were conducted—one each with school administrators, teachers, and parents of children attending the five schools.

Consistent with philosophical hermeneutic research, no limit was set to “power” nor was the study randomized. The number of participants in this type of research is determined by the richness of the data collected through strong exemplars about the topic of inquiry. When the topic is richly described or informed, data collection can be concluded (Moules et al., 2015).

**Data Generation and Analysis**

Data sources consisted of semi-structured interviews with eight individual participants, and the three focus groups with administrators, teachers, and parents. Informed consent was collected for each
participant. Individual interviews and focus groups varied from 30 to 100 minutes and were digitally recorded. The interviews were then transcribed verbatim for ongoing analysis. Field notes were written after each interview to capture contextual details and beginning interpretations.

A research interview guided by philosophical hermeneutics is characterized by its attention to the quality of the conversation, in which the questions became an invitation for the individual participants or focus groups members to engage with the topic (Hovey et al., 2014). The interview as a conversation is important because it is the means of developing extensive discussions that interconnect understandings and perceptions. The qualitative research team comprised an external non-Indigenous researcher (RH) and two Indigenous researchers (MP and AP).

Using a Two-Eyed Seeing approach, RH, who is an experienced philosophical hermeneutics qualitative researcher working with KSDPP for over 10 years, guided the interpretive analysis. The preliminary findings were closely reviewed in conjunction with two Indigenous researchers, including one with traditional knowledge who was also completing her PhD (MP) and one with her Master’s degree (AP). In hermeneutics, analysis is synonymous with interpretation and occurs in the complex dialectic of research interviews with participants and interpretive memos based on the transcripts. Through this in-depth, rigorous, reflexive, and communal attention to the data, the team collaboratively establishes the most relevant findings. Throughout the research, as with all KSDPP research projects, the research team presented regular updates about the research process, data collection activities, any challenges, and preliminary findings for discussion with the KSDPP CAB at their monthly meetings.

Results / Findings

The interviewees provided rich, in-depth accounts of how people in Kahnawà:ke view sleep and reflected on traditional ways; changing environments and the current way of living; facilitators and distractions to sleep, including technology in the bedrooms; and how sleep or a lack of sleep affects school and home participation of school-aged children (Hovey et al., 2014). The findings showed that a typical day in the life of a child may include attending school, homework, socializing, playing games, extracurricular activities, sports, and family expectations, constituting a busy life for students, parents, and grandparents.

The initially interviewed Elders and cultural knowledge holders shared that while dreams, and the interpretation of dreams, had a significant presence within the community—sleep was still sleep. In other words, understanding the sleep habits of children could be done without attention to dreams as a mitigating or culturally relevant factor.
The World Has Shifted

The world has shifted from watching the sun and watching the moon come up compared to putting on the light, putting on the computer, putting on TV, putting on movies, so they're distracted by all those things. (Elder participant).

The shifting world progresses and alters the way we perceive, watch time, and interact with our world. Only a few generations ago we depended upon the rhythms of the days, months, and seasons where the timekeepers telling us when to wake up and to go to bed. This way of life has faded away gradually and has been replaced with the technological interfaces that mediate our way of being with the world. The interface has changed dramatically the relationship human beings have with sleep and timing of when and how. The first finding from the research interviews directed our attention to the possibility that children were not achieving adequate sleep because of the negative influence of technology. This was especially true for children who had access to technologies in their bedrooms.

So what she sees with that, some of the kids come in and they’re really tired and she’ll ask what is going on and they’ll say “oh I stayed on my PlayStation until 2 in the morning.” Well, what were you doing up at 2 in the morning? . . . “I just didn’t listen. I just kept playing anyway.” (Teacher participant).

Parents, teachers, and administrators all pointed to the late-night use of cell phones, computers, televisions, and video games as reasons for the sleep deprivation they are witnessing with children. The use of these devices is a relatively new phenomenon; the generation before just had a family TV and a family phone and monitoring the use of these was simple compared to today.

In the Grade 6 classroom, I notice that the kids are 75% sleep deprived because they may have to go into their rooms at like 9 o’clock but they have access to the internet or their phones, music, and you name it. (School administrator participant).

Several participants identified children having access to technology in the bedroom as a particular problem, as it allowed them to stay up late with or without their parents’ knowledge.

The other one was the same issue as the screens, how to monitor the screens, to take the screens out of the bedroom and centralize places in the house because once they’re in the bedroom it’s hard to control, it’s hard to monitor, it’s hard to see what they’re playing, it’s hard to see how long they’re playing it. (Parent participant).

Technology in the bedroom was thought to make it more difficult to monitor and control what children are watching or playing, and how late at night they were staying awake. Some participants also
mentioned one negative impact the overuse of technology had on the imagination of children and their motivation to go outside, play, and be active. Several participants stated they did not allow televisions in their child’s room, maintaining that it created a more conducive sleep environment for the child to go to bed at a reasonable hour and get a more restful sleep.

Another participant spoke about their worry about children developing their imagination and creativity: “The biggest thing I see is that they have, they are being deprived of an imagination. They are given everything, there is no imagination left.” (Elder participant). This was supported by another participant who said, “In the long run . . . ’cause all their life they want to be entertained, entertained, entertained. Now there’s just too much distraction. Everybody has TVs.” (Parent participant). The loss of imagination means to become dependent on the thinking of others; creativity becomes limited by technological interpretations of the games we play, rather than games we invent, organize, and modify. The loss of imagination seems to be part of a cycle whereby children play games or watch screens (being entertained), which can keep them up late at night, and when they go to school their fatigue limits their capacity to imagine and be creative. The natural colours of the sun rising and setting are replaced by the artificial hues of computer screens and other devices.

Without imagination we lose the possibility of creating new ways of expression, negatively affecting art, culture, and intellectual curiosity and ways to solve life’s challenges.

**Parental Responsibility**

*Generally, my kids get 9 to 10 hours of sleep. They don’t have any health problems or anything. I make them go to bed at like 9 o’clock. I shut the TV off, they don’t have a TV in their room, and I shut everything off and they get in bed. (Parent participant).*

Another area often discussed in conjunction with technology, albeit controversial, was an absence of proper parenting.

*We tell them they have to . . . what time did you go to bed? Some of them say that they have TVs in their rooms, their bedrooms. Ah, a lot of technology in the bedrooms. Parents let them stay up late. (Teacher participant).*

This was a very sensitive issue but was pervasive throughout the interviews. One participant (parent) shared, “It is the parents who need the education, more than the kids. Because at this point they are the ones in control of the house.” Several participants believed it was up to the parents—“change has to be at home as well”—to ensure their children were achieving adequate sleep, and held the parents responsible for the sleep deprivation experienced by some children at school.
In school, I notice that a lot of the children are not sleeping as much as they should. They’re coming in and talking about shows that they watched and I know they’re on at 10 o’clock . . . some later. (Teacher participant).

Various parents were viewed as not setting appropriate limits for their children and allowing them to stay up late playing video games, talking on phones, or watching television. Several of the participants considered it the responsibility of the parents to better manage the household, and to set a good example for their children.

But actually, for me, that’s what has to happen. . . we need to get the kids healthy . . . mind, body, the parents need to become more involved, more responsible. (Parent participant).

The issue of being part of a blended family was also cited as being a possible disruption of home life, with the need to define or co-create “between homes” an adequate structure for their children. Children experience inconsistencies of living within two families, each possibly with their own interpretation of how children and sleep should be addressed and monitored.

**Kids Have Great Thumbs Now**

All you have is your brain, and outside . . . you don’t have the toys, you don’t have all that, you make up your own things. And our brain was continually working; all of our brain was working, not another brain working for us. Come the end of the day and you’ve had it. You are in bed and you are out like a light. (Elder participant).

Participants also discussed how the lack of outdoor physical activity was a significant contributing factor to children not acquiring adequate hours and quality of sleep.

And you’ve got to be tired. So, if you’re bored or you haven’t done anything all day, you’re not going to sleep well because you haven’t wasted enough energy to be tired . . . that’s where physical activity comes in. (Elder participant).

These participants felt that children staying inside all day playing video games and watching television led to their becoming more physically inactive, which negatively affected their sleep patterns.

Not anymore . . . you don’t even see the road hockey game like before. . . . I think the change, the big thing has been the computer, and the video games . . . kids have great thumbs now. (Elder participant).
Participants acknowledged the importance of feeling and being physically tired (from exercise) in order to get a good night’s sleep.

Yeah, we weren’t in the house all day like these kids. . . . How many kids are actually out playing now on their own besides organized sports, and that has a direct effect on their sleep. (Elder participant).

One person explained what helped their son become tired and sleep better:

I noticed that on certain days he was great because [he’d had] a full night’s sleep. And I was like, what are you doing with him to make him sleep? She said, “I make him run around the block.” (Parent participant).

Another parent observed the lack of children playing outside “like we used to” as having a direct adverse effect on their quality and duration of sleep, “because people when they’re tired . . . are very, very motivated to sleep.”

**Because the Food . . .**

We’re a boring house because you know lots of families have that . . . cupboard full of goodies . . . and we don’t have that, there’s nothing yummy to eat in the house. . . .

Anyway, if there was junk, they would have totally ate it . . . like chips or cookies or whatever . . . and then go to sleep with a full belly full of this crap. Instead they’re coming up and they’re having an apple . . . that’s why none of them have any weight problems. It’s true. So yeah, get rid of the cupboard and you can sleep. (Parent participant).

Several participants brought into the conversation the importance of proper nutrition, and the negative impact that junk food has on a child’s sleep.

Because the food . . . what they’re taking in during the day also has an adverse effect on their sleeping. . . . My son will eat toast with jam on it, Eggo waffles or he’ll have Sugar Crisp. (Parent participant).

They explained that more and more people are eating a diet full of processed foods, or “junk foods,” saying that our bodies are ill equipped to digest these kinds of foods, which are high in salt, fat, and caffeine. As a result, our bodies are unable to rest easily and therefore are stimulated by the digestion of junk foods. Many participants commented on the importance of having a healthy breakfast and lunch, and how that can help children do better in school: “And it’s all connected, you know . . . physical education, eating, sleeping” (Parent participant). The processed food has replaced the traditional ways of
eating that were part of being connected to the land, water, and earth. “You have to look at the thing that it’s easier to buy processed food in the package than actual healthy food” (Parent participant). This balance did not separate the person from a way of eating that promoted sleep, health and well-being.

The sleep and the food went together, they call it country food . . . they had better sleeping habits than people who ate frozen pizza, fries because it’s digested differently and so the body is resting differently. Or even late-night snacking, if you’re snacking while you’re looking at a screen, it’s different than if you’re having a meal with your family. Once lunchtime comes around or even snack time mid-morning, they open up their lunch box and there are all kinds of junk in there. So that might give them a little bit of energy boost but then as they get that high, they crash by the time lunchtime comes along. (School administrator participant).

Sleep and food are intertwined. “Country food” refers to a modality of eating food that is not processed but rather grown in local gardens or wild harvested with care and prepared in a way that nourishes the body. Country food speaks of not only the food itself, but also a way of being together as a family, where the events, concerns, and joys of the day are shared, processed, and addressed.

**Generation Gaps and Changing Times**

And as much as I love being able to go on my iPad and get a menu or talk to someone on the other side of the world, those conveniences that we appreciate, it’s their normal. And it’s made them a different generation. (Parent participant).

Many knowledge holders within the community perceived there to be a disconnection among community Elders, young parents, and the current generation, the children.

Before the bridge and everything came in, we were very active, we were always at the water, we were very community oriented, very family oriented; things have changed in the last 20 years. (Elder participant).

They believed this generational gap was leading to the adoption of a more Westernized perspective and the loss of cultural and family traditions. “I always slept with my mom, up until the time I was a teenager. All of us always slept with my mom. . . that’s how I raised my kids” (Parent participant). Several interviews and group discussions testified to the importance of learning from previous generations and valuing the knowledge that Elders possess. When the image on a screen replaces the imagination of a child there is a loss of learning to play, work, and interact with others.
There’s no imagination anymore. I remember when you were a kid, lunch is over and you would go and come back for supper, come back at dark. And you didn’t have anything and you made your own fun. They don’t do that now. If you threw a bunch of kids outside and you threw a bat, a ball, and a whole bunch of stuff. I don’t think some kids could even put together a pick-up game because they are always waiting for somebody to run it and organize it and set it up. (Elder participant).

Another participant spoke about how they observed that people within the community were working toward regaining a more wholistic way of life. This is a way of living that does not ignore the “old ways” but brings them into relevance within their lives (Hovey et al., 2014).

Younger people are going back to traditions and trying to go back to natural foods, healthier foods, organic. to be healthy and green, so and people are listening and understanding that there’s a change coming. The world is changing. they understand that we have to go back more towards our old ways because it was simpler. (Elder participant).

However, another participant spoke of the need for the younger generation to carry on the traditions but observed that children cannot be forced to care in a more meaningful way.

Because I see that today with some of the young parents in the Longhouse, they grab their kid and they sit them here and they have to sit and have to listen because they’re the ones that have to carry this on. If they’re not listening, then it’s going to be lost. (Parent participant).

The old ways are not just about how life used to be. There is recognition that returning to past ways of living a simpler life are more difficult given the influx of technology. While an ever-changing world may be beyond our control, the values, culture, and traditions that are foundational to this community need to be listened and interpreted into this new context of living or they will be lost.

Reflections Past and Present

Another finding within the individual interviews was the referencing of children’s behavioural changes as a personal reflection when compared to two or even three generations ago.

So I was amongst the children and I could see the differences from when my children were. you know when they were small and in school, I found it a big difference and I had a very hard time and having to cope with children who do not... it’s like they can’t hold their attention, you know? (Teacher participant).
One school volunteer, a grandparent, made the decision to stop volunteering because she found it difficult to cope with a new generation’s behaviour.

They want to stay up all night or sleep all day. There’s a time to be sleeping and it’s night and being awake during the day because of the, I guess you would say of the natural order, most humans are supposed to be sleeping. I mean you’re supposed to be sleeping at night and up at the crack of dawn. That’s what the stories are in the opening, that the birds when they start singing, that’s when you’re supposed to start getting up . . . that’s the opening prayer that everybody learns and that comes from the Creation Story. (Elder participant).

Two or three generations ago, children were more physically active outdoors, to the point where they were so exhausted at the end of the day, sleep time was welcomed. Children spent more time with grandparents, who taught about eating well and “taking care of yourself” through adequate rest. It was mentioned that the economy was much different—“we were all poor.” Another said, “We all had gardens and chores . . . all of these things kept us occupied and literally tired us out.” Another sign of changing times, as articulated in one interview, was that not too long ago, most pregnant women were not in the workforce and therefore spent more time at home learning about how to bewholistically well during pregnancy. In the past, mothers and grandmothers would teach expectant mothers about proper practices of care for themselves when pregnant. These teachings retained the connection to the creation story; the voice of mother to daughter, grandparents to grandchildren kept the stories alive as they were carefully and purposefully passed on to the next generation. This personal family connection not only served to pass on knowledge, traditions, and culture, but also promoted and strengthened relationships.

In another interview, a teacher spoke at length about how we live very differently, stating that the children of today “want to stay up late and sleep during the day.” Part of the cultural relevance of the “Thanksgiving Address” was being up early to recite it each morning; one parent said it would be recited “when the birds start singing.” This is difficult when children cannot wake up early to welcome the new day. Gadamer (1996) wrote:

The mystery of sleep seems to me to be one of those fundamental experiences in which our human self-understanding reveals itself both as something continuous with nature and yet as something which constantly strives towards establishing the new. Every morning of every day each of us experiences the promise and the risk involved in a new day and a new morrow. It is precisely here, in the movement between sleep and waking, between relaxation and exertion, that we encounter the particular constitution of human beings, their capacity to abandon themselves to the pursuit of the most daring goals while retaining their own self-identity. (pp. 85–86).
Gadamer reminds us of the potential found in and through sleep, not only as a health benefit, but also its effect on imagination, physical activity, and self-identity. Although we cannot return to the times of our parents and grandparents, we can retain their messages, values, beliefs, and wisdom through a reinterpretation first imagined and then practised in a modern context.

Discussion

Parents, Elders, and cultural knowledge holders were aware that a lack of sleep was affecting how well their children were doing in school, both academically and behaviourally. For example, several parents mentioned that their child’s teachers had phoned with complaints about inattentiveness, misbehaving, grumpiness, and fatigue. The majority of parents agreed that televisions, cell phones, and video games were among the greatest distractions for their children. Some parents said they did not always know when their child was asleep; having a television, computer, or video game device in the bedroom encouraged children to stay up late into the night and sometimes the early morning.

In general, parents were receptive to the idea of introducing a sleep curriculum into the schools. However, they were concerned about whether it would become more homework for their children. Other parents thought this could be a great way to build up self-esteem and self-efficacy in the children—through knowledge. The parents also felt that it would help them within their family dynamic to make informed decisions as parents with other family members if the schools provided this information. They also expressed that children may feel empowered through sharing knowledge about sleep being essential for success.

Teachers have noticed an increase during the past few years in the number and frequency of students falling asleep at their desks, unable to do their work, and being “grouchy” and “hypersensitive”—all of which may be attributed to a lack of sleep. Several teachers mentioned that parents were not setting proper time limits with their children and were letting them stay up late into the night or even into the early morning because of electronic media or televisions in their bedroom. This could explain why some of the children are “really tired” in school, as even moderate amounts of sleep loss (30 to 60 minutes) can be cumulative and can have a significant negative impact on alertness and cognitive learning (Gruber et al., 2012). Teachers supported the importance of children participating in daily physical activity to feel physically and healthily tired. Overall, teachers were receptive to incorporating sleep materials into the current health curriculum, although concerned it should not become onerous.

Administrators, as did the parents and teachers, shared a concern for the negative influence of having a television and/or electronic media located within the child’s bedroom. They also spoke to the lack of proper sleep schedules, unstable routines, and lax parenting habits as reasons why children were not achieving adequate sleep. The emphasis among administrators was on the importance of parental
involvement. They asserted that since parents are in control of the house and also needed the sleep education. Administrators were receptive to the possibility of a curriculum on sleep, provided that it could be flexibly integrated into existing subjects.

The home activities that are keeping elementary school children awake in Kahnawake are not uniquely different from those for children in other communities, and the parent, teacher, and administrative focus groups all expressed that a lack of sleep had an effect on school performance, participation in other activities, and family life. Other studies show that children are sleeping less than previous generations (Matricciani, Olds, & Petkov, 2012), and that many children have electronic media in their bedrooms and are using technology late at night (Chahal et al., 2013), resulting in later sleep onset (Foley et al., 2015) which adversely affects sleep duration (Cain & Gradisar, 2010).

In terms of sleep hygiene practices, our findings from Phase 2 supported the concerns of those who were interviewed, as half of children age 3–5 and almost three quarters of those age 6–12 have TVs and other electronic media in their bedrooms and many are using them past their bedtimes (Seganathy, 2014). The Canadian Pediatric Society recommends children do not have TVs in their bedrooms and also recommends limiting screen time for children to 2 hours per 24 hours (Lipnowski & LeBlanc, 2012); however, many children are exceeding this recommendation past their bedtimes (Seganathy, 2014). Televisions in children’s bedroom have also been associated with gaining excess body weight (Chahal et al., 2013), putting children at risk for obesity and Type 2 diabetes later in life. Conversely, increased sleep duration results in lower reported food intake and lower body weight (Hart et al., 2013). The caffeine intake reported in this study is within the amount allowed by Health Canada (2012) for these age groups, so this is not a concern (Seganathy, 2014). The updated information on consumption of iced tea and soft drinks is very useful information for KSDPP intervention staff. KSDPP has always emphasized that these drinks contain high amounts of sugars and therefore will continue to recommend that children drink water, milk, and small amounts of fruit juices.

Limitations

Fundamentally, the concept of limitations in research is a quantitative construct that is not completely transferable to qualitative research, in particular for philosophically based research such as hermeneutics and phenomenology. However, the ability to conduct rigorous qualitative research is found in the academic training and lived experiences of the Indigenous and non-Indigenous qualitative researchers. This translates to how well the researchers understand the philosophical foundations of the research approach, generate purposeful questions, and interpret the narrative data. A Two-Eyed Seeing approach helped us to develop a common understanding, language, and commitment among the researchers and community toward completing this research project. Based on these criteria and because of the numerous discussions with community Indigenous researchers and CAB we believe we asked the right questions, the right way, to the right groups of research participants who best informed the
intention of this study. Certainly, what we learned from this study did generate more potential research questions, but this is not a limitation but rather how qualitative research works.

For the second phase, after informing the community through the local media and working with the teachers about the reasons for collecting information on children’s sleeping habits, we sent home questionnaires with the children to the parents of preschool and elementary school children, because this approach has worked well for previous KSDPP data collections. The questionnaires had all been reviewed by CAB members and included information as to how parents could contact the Indigenous research coordinator if they had any questions. The questionnaires asked about the presence of electronic media in children’s bedrooms and use after bedtime, and soft drink intake. Only 24% of parents of preschool children and 12% of parents of elementary school children answered the questionnaires, and we cannot tell if the responses are representative of children living in the community. CAB members who reviewed the results believe this low response rate was due to parents being overwhelmed with three KSDPP requests at the same time. After detailed internal KSDPP discussion, this bundling had been an attempt to minimize paperwork for parents, but we believe it failed because it overwhelmed the parents by presenting them with three different research questionnaires at the same time within one research package.

**Conclusion**

To our knowledge this is the first research project to evaluate sleep for Indigenous preschool and elementary school children. Given the importance of healthy sleeping habits to overall health and academic learning, we hope that others will undertake similar studies. These results have been widely disseminated within Kahnawà:ke, through the local newspaper and radio station and community presentations. Through the co-development and adoption of a Two-Eyed Seeing approach, all voices—Indigenous and non-Indigenous—were valued contributions to this research. This process of working together began several years before this study was conducted, with the relationship among the researchers already well established. This relationship facilitated working on this study because we had already had time to learn deeply from each other (Hovey et al., 2017).

Since finalizing data collection, a team of KSDPP intervention staff, cultural knowledge holders, community artists, curriculum developers, and KSDPP research team sleep experts have combined their skills, traditional knowledge, these results, and national recommendations to finalize a culture- and age-appropriate sleep-promoting curriculum. The curriculum, with associated lesson plans for Grades 1–6, will promote healthy sleeping habits in the preschool and elementary schools and supply educational materials for the entire community. All materials were discussed in detail with the Kahnawake Education Center and staff of all the elementary schools and the preschool. The Indigenous research coordinator has been invited by participating schools to present on healthy sleep habits to parents at the welcoming and information sessions. The same team also developed a book that follows the life of a family in traditional times and shows how sleep was an integral component of daily life and is now
finalizing a book that follows a modern family living today. The first book was launched by one of the Indigenous researchers through a reading to elementary school children and their parents at the Kahnawà:ke community library, and copies written in both Mohawk and English have been donated to the library and the schools. The books will also be given to all parents who participated in the study.

Our research has revealed that a successful intervention for sleep must include parents, teachers, school administrators, and the support of the community. Otherwise a fragmented intervention will fail to provide a cohesive approach to improve sleep hygiene and achieve adequate sleep for children in Kahnawà:ke or elsewhere. We believe that undertaking this research project has increased community knowledge about the importance of sleep, and the resulting interventions to promote healthy sleeping will contribute to community empowerment and decreased rates of Type 2 diabetes.

References


Community-Based screening and triage versus standard referral of Aboriginal children: a prospective cohort study protocol.

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Community-Based screening and triage versus standard referral of Aboriginal children: a prospective cohort study protocol.

Abstract
Health solutions for Aboriginal children should be guided by their community and grounded in evidence. This manuscript presents a prospective cohort study protocol, designed by a community-university collaborative research team. The study’s goal is to determine whether community-based screening and triage lead to earlier identification of children’s emotional health needs, and to improved emotional health 1 year later, compared to the standard referral process. We are recruiting a community-based sample and a clinical sample of children (ages 8 to 18 years) within one Canadian First Nation. All participants will complete the Aboriginal Children’s Health and Well-being Measure (ACHWM)© and a brief triage assessment with a local mental health worker. All participants will be followed for 1 year. Children with newly identified health concerns will be immediately connected to local services, generating a new opportunity to improve health. The development of the research design and its execution were impacted by several events (e.g., disparate worldviews, loss of access to schools). This manuscript describes lessons learned that are important to guide future community-based research with First Nations people. The optimal research design in an Aboriginal context is one that responds directly to local decision makers’ needs and respectfully integrates Aboriginal ways of knowing with Western scientific principles. Such an approach is critical because it will generate meaningful results that will be rapidly adopted, thus reducing the knowledge-to-action gap.

Keywords
Prospective cohort study, Aboriginal, children, mental health, screening

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Background

Aboriginal\(^4\) children and youth\(^5\) are the fastest growing segment of the population in Canada (Canadian UNICEF Committee, 2009; Statistics Canada, 2011). These citizens experience serious health inequities (Blackstock & Bennett, 2003; Canadian UNICEF Committee, 2009, 2012; Smylie & Adomako, 2009). For example, the rate of youth suicide is 5 to 6 times the national average (Advisory Group on Suicide Prevention [Canada], 2003; Canadian UNICEF Committee, 2009), and suicide/self-inflicted injury is the leading cause of death among Aboriginal youth (Adelson, 2005). Within the province of Ontario, rates of emotional health crises are highest in northern and rural communities, where the rates of physician visits for emotional health support are lowest (MHASEF Research Team, 2015).

First Nations represent 61\% of the Canadian Aboriginal population and are the focus of this protocol. In Ontario, there are 133 First Nations reserves (Chiefs of Ontario, 2015), and most are geographically isolated. First Nations ranked 68th while Canada ranked third on the Human Development Index, a composite measure of life expectancy, education, and average income (Canadian UNICEF Committee, 2009). First Nations have scored consistently lower on the Community Well-being Index, with a deficit of approximately 20 points (Aboriginal Affairs and Northern Development Canada, 2015).

On-reserve health services have the capacity to deliver health promotion, prevention, early intervention, and counselling (White & Jodoin, 2004), yet many families seek emotional health support for children only during an acute crisis. Since intensive or specialist-based services are not available on reserves, children are often forced to leave their communities to seek services hundreds of kilometres from home, away from family supports (Nagarajan, 2004).

To achieve better alignment between the needs of First Nations children and the scope and capacity of on-reserve services, we must identify the needs of this population earlier. That requires recognizing children’s need for support when their emotional health needs are emergent rather than urgent, and connecting children to culturally sensitive and efficacious support services within their own community. This protocol aims to turn attention to population health promotion and secondary

\(^4\) The term Aboriginal in this paper includes First Nations, Inuit, and Métis, and is the term preferred by our community partner.

\(^5\) The term children is used in this paper to include both children and youth up to the age of 18 years.
prevention, and to engage the full scope of services, beyond specialist and physician care. It is in line with the Ottawa Charter for Health Promotion’s recommendation to focus upstream (Mahler, Epp, Franklin, & Kickbusch, 1986), and with the Mental Health Commission of Canada’s Strategic Plan (Mental Health Commission of Canada, 2016). Both documents highlight prevention strategies as critical in isolated communities. This protocol attempts to “develop and carry out locally-driven community plans for preventing suicide” as outlined in Canada’s National Aboriginal Youth Suicide Prevention Strategy (Health Canada, 2013). In other words, this project began with a strengths-based intention to paddle upstream towards wellness.

The screening tool embedded within the Aboriginal Children’s Health and Well-being Measure (ACHWM)\(^6\) is a strategy for earlier identification. The ACHWM was developed by Aboriginal children and health providers, in collaboration with academic researchers (Young et al., 2013; Young, Wabano, Ritchie, et al., 2015; Young, Wabano, et al., 2016; Young, Wabano, Usaba, et al., 2015). It is completed independently by children (8 to 18 years), using Android tablets. The ACHWM is able to identify at-risk children (Young et al., 2017) in a way that is culturally appropriate and feasible in isolated Aboriginal communities (e.g., First Nations) and is tied to rapid triage and access to treatment resources. Previous testing of the ACHWM’s screening and triage process took place from 2014 and 2015 (Young et al., 2015; Young et al., 2016; Young, Wabano, Usaba, Trottier, & Burke, 2014). Results indicated that 18% of children were at risk, and most had not previously been supported through standard practice (Young et al., 2014; Young et al., 2015; Young et al., 2016). The screening algorithm has good psychometric properties in this setting: a positive predictive value of 84.5% and a negative predictive value of 94.7% (Young et al., 2016).

The purpose of this study protocol is to evaluate the effectiveness of screening, triage, and subsequent treatment on the emotional health of children living in a rural First Nation. This paper describes the protocol and reports on the experiences from the planning and implementation stages of this project, with the goal of informing future research.

**Methods**

This research is guided by the First Nations Mental Wellness Continuum Framework (Health Canada, 2015). The framework articulates essential services, beginning with “Health Promotion, Prevention, Community Development, and Education” and “Early Identification and Intervention” (Health Canada, 2015). The social determinants of health model (Greenwood & de Leeuw, 2012; Mikkonen & Raphael, 2010; Raphael, 2009) also plays a pivotal role. Most important, this protocol was designed with, and for, a First Nation. This protocol is in the implementation stage at the time of writing.

\(^6\) Aboriginal Children’s Health and Well-being Measure\(^5\) is a registered copyright of N. L. Young, M. J. Wabano, and S. D. Ritchie.

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Relationships

Our team includes a mix of Aboriginal and Western clinicians and scholars. The leaders of this project (MJW and NLY) bring expertise from the community and the academy. They have a history of respectful collaboration that has spanned almost a decade and eight previous collaborative projects. The trust and respect within this relationship is an important component. The leaders expanded the team for this project, bringing in additional expertise, carefully balanced to reflect and respect diversity and ways of knowing.

Research Question

This protocol answers one overarching research question: *Does the ACHWM screening and triage process lead to earlier identification of needs and better emotional health outcomes among Aboriginal children, compared to the standard referral practices?* Note that the term *earlier* refers to the stage of their illness trajectory rather than age (i.e., while their needs are first emerging).

Design and Justification

This protocol is evaluating a potential solution to a high-priority issue on First Nations reserves in northern Ontario: children’s emotional health. It supports the community’s direction to move towards community-based screening. We are following the guidance of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010) and fulfilling the OCAP principles: ownership, control, access, and possession (Schnarch, 2004).

We are currently conducting a prospective cohort design with a 1-year follow-up period, to compare the emotional health of children who access on-reserve emotional support services through two different referral processes and to healthy peers. This approach is appropriate for community-based research and congruent with Aboriginal worldviews (Ten Fingers, 2005). It is also consistent with best practices for research with Aboriginal communities (Brant Castellano, 2004; Canadian Institutes of Health Research, 2010; Maar et al., 2011; Noojmowin Teg Health Centre, 2003; O’Neil, Elias, & Wastesicoot, 2005; Saylor & Blackstock, 2005). The potential for rapid uptake of findings into practice is enhanced because this design responds directly to local needs. Our protocol is informed by the “Strengthening the Reporting of Observational Studies in Epidemiology” guidelines (Von Elm et al., 2014).

Balancing Western science and Aboriginal ways of knowing.

Our goal from the outset has been to blend the strengths of Western science with Aboriginal knowledge, an approach that has been referred to as Two-Eyed Seeing (Bartlett, Marshall, & Marshall,

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7 OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC; www.fnigc.ca).
2012; Martin, 2012). While randomized controlled trials (RCT) are strongly favoured, such approaches have been critiqued in the context of research with Aboriginal Peoples for being heavily laden with imperialism and colonialism that influence the gaze of the researcher, and for privileging Western perspectives over Aboriginal ways of knowing (Smith, 1999). Our approach aims to follow the recommendations from the Truth and Reconciliation Commission of Canada (TRC, 2015b) to close gaps in outcomes between Aboriginal and non-Aboriginal communities (Call to Action #19) and include Aboriginal voices to help provide guidance on the needs of Aboriginal people to improve health care access and processes.

The privilege afforded to Western experimental designs over Aboriginal worldviews is not uncommon (Ten Fingers, 2005) and presented several unique challenges in the process of grant development. An RCT offers scientific rigour; however, several requirements, such as blinding and randomization, were neither feasible nor appropriate in this community. Furthermore, the externally controlled nature of an RCT is viewed by many Aboriginal Peoples as contravening their autonomy and sovereignty; it also introduces selective participation and threatens the external validity of RCT results (Eap & Nagayama Hall, 2008; Lau, Chang, & Okazaki, 2010). Moreover, RCTs “may be useful tests of efficacy but rarely allow an evaluation of effectiveness” (Sanson-Fisher, Bonevski, Green, & D’Este, 2007). A potential limitation is their lack of external validity (generalizability) (Bowling, 2009; Cummings, Grady, & Hulley, 2007; Sherman et al., 2016). Because of these limitations, an RCT design would not generate evidence to change practice in the context of Aboriginal children’s health. A comparative, prospective cohort design is the most appropriate study design to answer our research questions. This design is also a good fit for the research capacity of the community and offers an opportunity to generate scientific evidence, while being inclusive and respectful of Aboriginal worldviews and values.

Setting
This protocol is being conducted on the Wiikwemkoong Unceded Territory, the largest rural First Nation in Ontario, with 547 members (17%) between the ages of 8 and 18 years (Band Council Secretary, 2016). The leadership of Wiikwemkoong has been proactive in developing new strategies to promote better health outcomes, with a specific focus on children (Wiikwemikong Chief and Council, 2013). The development of the Aboriginal Children’s Health and Well-being Measure (ACHWM) began in this First Nation, and the mental health workers in this community originally identified the opportunity to embed an emotional health screening and triage process within the ACHWM. The rural location of this First Nation, located 2.5 hours (175 km) from the nearest urban centre, reduces the influence of urban services, making it a relevant microcosm in which to assess the impact of screening and triage. It has the health care resources necessary to respond to screening results, making it safe and relevant to conduct the proposed research. The findings from this study will be highly relevant to many other First Nations.
Participants

Children between the ages of 8 and 18 years who are members of Wiikwemkoong Unceded Territory are being recruited in two different ways: a community-based sample from schools and community events; and a clinical sample at intake into Nadmadwin Mental Health clinic, the primary emotional support service provider in Wiikwemkoong. School-based screening is recognized as a best practice for harm reduction (Kutcher & Szumilas, 2008; Scott et al., 2009). Secondary prevention is most effective in high-risk populations (Clifford, Doran, & Tsey, 2013; Robinson et al., 2013).

The recruitment process includes sending information letters and consent forms to homes and schools, connecting with children at community events through information booths, and sending individual invitations to all children who have recently begun receiving emotional support services. Written informed consent and assent for the project are being obtained and securely stored in the health records office at Naandwechige-Gamig Wikwemikong Health Centre.

Variables and Measures

There are two main outcomes of interest: (1) timing of the identification of participants’ needs for emotional support; and (2) emotional health 1 year later. Identification is determined by clinician assessment. The timing component is determined by level of emotional health, with higher scores at identification suggesting an earlier stage of their illness trajectory. Emotional health is being measured using the emotional quadrant (EQ) score of the ACHWM.

*The Aboriginal Children’s Health and Well-being Measure (ACHWM).* The ACHWM is a self-reported health assessment tool developed with First Nations children in Wiikwemkoong (Young et al., 2013). It endeavours to move beyond the biomedical model of illness to understand the health and wellness of Aboriginal children through a culturally informed model. It is conceptually grounded in the Medicine Wheel framework (Dumont, 2005) and assesses spiritual, emotional, physical, and mental health to generate a wholistic picture of children’s wellness (Young et al., 2013). Scores range from 0 to 100 and higher scores indicate better health. In addition to being culturally appropriate (Young et al., 2013; Young, Wabano, Ritchie, et al., 2015), it is also valid (Young, Wabano, Ritchie, et al., 2015; Young, Wabano, Usuba, et al., 2015) and reliable (Young, Wabano, et al., 2016). In the hands of First Nations health leaders, the ACHWM process enables solutions to come from within each community (Saylor & Blackstock, 2005) and fosters empowerment (Chandler & Lalonde, 2009). The ACHWM is relevant to other communities (Baker-Anderson et al., 2015; Paquette, Boulard, Roy-Charland, & Young, 2014; Young et al., 2017) and has the support of the Chiefs of Ontario Band Council Resolution #13/15. The EQ score is the average of responses to 24 questions and is a marker of emotional health.

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8 The term *wholistic* is preferred over *holistic* because it is based on “whole,” meaning interconnection of several parts to form a whole, rather than a gap as would be implied by “hole.”
Our previous analyses of the psychometric properties of this ACHWM subscale (e.g., Cronbach’s α = .88) indicated that it satisfies key criteria necessary for a primary outcome (Young et al., 2016). The EQ score is the primary outcome in this study.

**Other measures.** Additional information on treatment is being gathered for all participants treated at the local mental health clinics. This information includes: diagnostic codes, number of clinical visits, number of missed clinical visits, other health services utilizations, type of services, duration of service, clinical progress, and critical incidents. Location of services (on vs. off reserve) and type of provider are also being recorded.

**Procedures**

All participants are being asked to complete the ACHWM on tablets at intake into the study (baseline). Data are being stored using ID codes, uploaded to a REDCap (Harris et al., 2009) server at Laurentian University (https protocol), and reviewed for any errors or omissions at the end of each implementation day. This system offers a high level of data security, is backed up daily, and provides the community partners access to their data through our server as specified on our sharing agreement.

**ACHWM screening and triage process.** The ACHWM screening and triage process previously described by Young, Jacko, et al. (2016) is being applied to identify emergent emotional health concerns. The ACHWM identifies potential risk in real time based on responses to 18 screening items. The ACHWM Android tablet application executes the preprogrammed screening algorithm, then displays and prints a screening report showing flagged responses, summary scores, and all quadrant scores including EQ. Screening results for each participant are immediately shared with a local mental health worker (MHW) on site, who conducts a brief assessment with each child in private to determine their risk status (not at risk or at risk). The MHW then triages at-risk participants to appropriate emotional health supports (e.g., one-on-one counselling or services of a traditional healer).

**Group Assignment**

The *children recruited in the community* are being divided into two groups based on the MHW’s assessments: the subgroup who are not at risk form the healthy peers group (HP), and the subgroup who are at risk form the newly identified needs (NIN) group. The *children recruited in the clinic*, and who are in the early stages of treatment (with 3 months since diagnosis), form the typical treatment group (TT). The group assignment is summarized in Figure 1.
All three groups are being followed for 1 year from baseline. The HP group are being assessed at baseline and 1 year later using the ACHWM. The NIN and TT groups are being referred to local MHWs for support according to usual clinical protocols in this community. These participants are to be reassessed using the ACHWM at quarterly intervals until the end of the follow-up period (i.e., 1 year from baseline). MHWs treating participants in the NIN and TT groups are to submit a quarterly report on each participant’s use of mental health services and progress. These data will be used to support the exploration of cost implications related to the ACHWM screening and triage process.

Analyses
Descriptive statistics will be used to summarize the demographic characteristics of the study groups, including age, gender, the ACHWM overall score, and the four ACHWM quadrant scores. The amount of missing data and reasons for missing data will be used to determine the imputation plan for incomplete variables, including missing longitudinal measures (Van Buuren, Brand, Groothuis-Oudshoorn, & Rubin, 2006). The modelling strategies described below will then be applied to each imputed data set to answer our overarching research question: *Does the ACHWM screening and triage process lead to earlier identification of needs and better emotional health outcomes among Aboriginal*
children, compared to the standard referral practices? This overarching research question will be divided into two subquestions for analysis.

To what extent does the ACHWM screening and triage process enable the identification of needs earlier in the illness trajectory, among Aboriginal children, compared to the standard referral process?

This question uses the term earlier in reference to stage of children’s emotional health trajectories rather than age, and has been operationalized based on EQ scores at baseline (where higher scores indicate better emotional health or an earlier stage of illness). This question will be answered by comparing EQ scores at baseline for the NIN group (identified via the screening and triage process) to those of the TT group (identified through traditional referral mechanisms and receiving emotional support from local MHWs).

We will use a linear regression model of EQ scores at baseline with group (NIN vs. TT groups) as the independent variable, generating point estimates (and 95% confidence intervals) that will quantify the differences at baseline between those identified through screening compared to the usual referral process. We will also include covariates in this model to adjust (using inverse weighting with propensity scores) for the influence of age at baseline, gender, and which school they are attending.

To what extent does the ACHWM screening and triage process contribute to better emotional health 1 year later for at-risk Aboriginal children (NIN group), compared to the standard referral process (TT group)?

To understand the impact of the screening component on emotional health trajectories over 1 year, we will graph the distribution of EQ change scores as a function of time for each of the groups: NIN, TT, and HP. Box and whisker plots will be used to examine the changes in each of these groups. These graphs will demonstrate the pattern of change in each group. We will use a linear regression model to compare the 1-year EQ change scores between the NIN and TT groups, relative to the HP group to adjust for any changes over time in the general population’s EQ scores. This regression will also include adjustment for age, gender, and school. The HP group will form the reference (or control) group to adjust for any changes in health that occur in children who are not receiving treatment. The comparison of the NIN to HP group will determine whether or not there is a significant improvement in health in the NIN group, over and above the underlying trend in child health in this community, as demonstrated by the HP group. The comparison between the NIN and TT groups will determine whether treatment of the NIN group is more or less effective than treatment beginning at the usual point in the health trajectory.
The clinical expectation for EQ change scores over 1 year is moderate improvement in the TT group; greater improvement in the NIN group due to better fit between their needs and the scope and capacity of local services; and no change or slight decline in the HP group.

Bias

To minimize systematic bias, we have established standardized training, and all scoring and screening processes have been automated. During the development of the ACHWM, considerable effort was made to reduce random errors from participants though standardized testing protocols and information-gathering methods. Children are completing the ACHWM in a quiet, nondistracting environment. We acknowledge that there may be selection bias, with a tendency to recruit children with better health (early adopters), which has the potential to bias the generalizability of our findings. Thus, caution will be exercised in the interpretation of results. We also recognize that there may be events in the community (either positive or negative) that may influence ACHWM scores. The inclusion of the HP group will permit us to account for any systematic change in the population during the study period.

Sample Size Estimation

We designed this study to include 250 children (46% of the target population) between the ages of 8 and 18 years to complete the survey at school or at a community event. Within this sample we expect 45 children (18%) to be at risk (NIN group) (Young et al., 2016), leaving 205 in the HP group. We expect the TT group to include approximately 60 children as part of the standard referral practices, based on referral records at Nadmadwin for 2014 and 2015. Attrition at 1-year follow-up is expected to be high, but the magnitude is unknown. However, all participants will be attending local schools or Nadmadwin. These sites provide an excellent opportunity to maximize follow-up.

The baseline EQ mean (and standard deviation) for the HP group is estimated to be 77.7 (11.3) and the EQ mean for the NIN group is estimated to be 56.5 (10.8), based on 2014 and 2015 data from this community (Young et al., 2014; Young et al., 2015). We also know that the EQ mean for children reporting “good” health has been 10 points higher than the mean for those with “fair” health in previous studies (Young et al., 2014; Young et al., 2015). With our expected group sizes, an alpha of .05, and a standard deviation of 11 points, the study will have 80% power to detect a baseline EQ score difference of 6.1 points (a medium effect size).

Discussion

This protocol was developed by a diverse interdisciplinary team who were carefully selected to support a Two-Eyed Seeing approach (Bartlett et al., 2012; Martin, 2012). To inform future work, we discuss the lessons learned through both the planning and implementation stages.
Lessons Learned Through Planning

It became apparent in the early stages of developing this protocol that many aspects of the design could be approached in substantively different ways (Aboriginal and Western) that were not easily reconciled. For example, the team had two different approaches to the research question. The overarching question that developed in collaboration with Aboriginal community and academic partners was: Does the ACHWM screening and triage process lead to earlier identification of needs and better emotional health outcomes among Aboriginal children, compared to the standard referral practices? For the submission of the protocol, the funding agency required the research question in PICOT format (population, intervention, comparison group, outcome, and time) (Guyatt, Rennie, Meade, & Cook, 2008; Haynes, Sackett, Guyatt, & Tugwell, 2006; Rios, Ye, & Thabane, 2010): Compared to the standard referral process, does the ACHWM screening and triage process enable the identification of children’s needs earlier in their illness trajectory and result in better emotional health over 1 year, for at-risk children living on a reserve? This format reflects a Western perspective. Furthermore, the PICOT format was not acceptable to the community partners and several of the academic partners. In this manuscript, both question formats are presented. However, we are focusing on the first non-PICOT question, because we have the shared aim to improve tailored health systems and practices by creating innovative, patient- and community-centred research approaches, and because we have a community as our partner and their children as our priority. The nuances of the two variants of the question underscore one of the challenges of working in two paradigms.

Some challenges arose that were unfamiliar to some of the collaborative members, such as the need for approval from the local Chief and Council in the form of a Band Council Motion in addition to the standard approvals from the university and the Research Ethics Board. Community engagement, reciprocal dialogue, and Chief and Council approval are essential to respect the sovereignty of the First Nation.

It was clear that nuances of language had great significance as we progressed in writing this manuscript and received feedback from both community and academic partners. The weight of the implications of some terms became apparent. For example, the use of the term privilege, (Beavis et al., 2015) was important to consider due to the gravity of its meaning to Aboriginal people. The weight of this word was not initially appreciated by all scientists within the team, and through the writing we moved towards a better understanding of critical terminology. The nuances of clinical terminology versus scientific terminology versus community practice terminology were also distinct and required careful consideration, such as the term emotional health versus mental health. In Anishinaabek teachings, feelings are part of “emotional wellness,” yet in Canadian society the equivalent term is “mental health.”
The team considered registration of the design with the primary clinical trial registry at www.isrctn.com; however, it became apparent that the categories and language used in the registration process (e.g., “condition” implies disease) did not adequately fit the community-based population sample described here. Our goal is to give voice and power to community members and build strength, in keeping with the recommendations for research with Aboriginal Peoples in Canada (Baydala, Saylor, & Ruttan, 2013). We are respectfully electing to share the methods through this publication, rather than via a clinical trials registry.

The team also developed strategies to share information about the project and to link partners across distance. There were unique requirements to fit with the context (e.g., need for processes that worked outside of Wi-Fi and with low Ethernet connectivity). There was also extensive relationship building and education on both sides of the team, including developing an understanding of Aboriginal culture among scientific partners. This was achieved through weekly phone meetings and monthly face-to-face meetings to build and maintain relationships across the core team; file sharing between all members of the team; and data sharing with a limited number of community and academic partners via REDCap (Harris et al., 2009). While not optimal, these solutions met the needs of this collaboration. Screen sharing and toll-free dial-in numbers were provided for most team meetings, to ensure review of all pertinent material both visually and through verbal discussion. The first full team meeting was held on the traditional territory and was an important contextual learning experience for the academic team, several of whom had little or no experience of life in a First Nation. It aided in developing relationships that are essential to respectful collaboration.

**Lessons Learned Through Implementation**

Through the implementation of this design, several key lessons were learned that were not expected by a few members of the team, and thus are important to share. First, the time required to initiate the project was significantly extended. This was due to the need to further develop collaborative relationships across the extended team, obtain engagement of all involved, secure the subgrant agreements through the university, and hire local staff in an environment with limited human resources.

Second, on-reserve clinical services were continually evolving, both as staff transitioned in and out of positions, and in response to local policies. For example, the local MHWs were employed through an intermediate agency, and additional approvals were necessary to gain access to these key staff. The study could not be fully implemented in their absence. In addition, the MHWs had grown accustomed to having information from the ACHWM to inform their counselling. Thus, it was important that the local MHWs be able to use the measure with all new clients, not only those who consented to the study. The consent process was modified to permit the ACHWM to be used as part of clinical practice, with consent obtained later to share the clinical results with the research team. The timing of consent was thus delayed to ensure the clinical needs of the children were not compromised by the consent process. We also learned that many participants wanted to have the consent discussion with the MHW who was
providing their treatment. We identified that choice was important in this consent process and
determined that the children should be the ones to choose. Participants were offered the option to speak
to another staff member about a related research project or to have that discussion with their clinician.
This process was approved by the Laurentian University Research Ethics Board (6008139 & 6008433).

The ethics approval was achieved efficiently, as was Chief and Council approval, due to the
strong, positive, and longstanding relationships between the team and these organizations. Recruitment
began smoothly but was later compromised by a change in the interpretation of Board of Education
policy. Given the community-engaged nature of this study, working within the guidelines of local
agencies was imperative. The team discussed alternative recruitment strategies, such as recruiting
through community events and at the local health centre, to compensate for lack of access to the schools.
The team also connected with two neighbouring First Nations to permit recruitment of additional
participants.

Finally, a key issue in the study was potential for loss of follow-up. This may be related, in part, to
seasonal migration to and from the reserve. The tracking of all participants through the period of the
study has been uniquely challenging and critically important. We have also discovered that members of
the NIN group may choose to seek services away from the reserve to ensure greater privacy, since there
may be familial ties to some service providers within this isolated community. They may also wish to
access more intensive or specialist-based services. These concerns are unique to remote communities,
and add to the complexity of research with isolated communities (Ritchie et al., 2013).

Conclusions

This manuscript presents an evaluation protocol for Aboriginal emotional health that integrates
Aboriginal ways of knowing and Western scientific principles. This blended research approach is not
well known in the scientific community and infrequently published in the literature. The unique
challenges this diverse team faces, including the challenge of maintaining a balance between the
paradigms, present unique learning opportunities for those embarking on research relevant to Aboriginal
populations, including scientists and community leaders looking to build partnerships with researchers.
Hence publication of the protocol and unpacking key challenges and solutions are important for future
research.

Our collective observations to date underscore the importance of capturing data that go beyond the
traditional quantitative outcomes. These observations pertain to both the process and outcomes of the
research. Through our process we recognize the need to add a qualitative component to capture the
broad impacts of this study. This approach is acceptable in the community and will allow for greater
exploration of the mechanisms contributing to meaningful impacts and outcomes. The selection of
methods that are in keeping with local practices and ways of knowing is critical to reducing the
knowledge-to-action gap (Graham et al., 2006; Maar et al., 2011; Straus, Tetroe, & Graham, 2013).
Our observations are consistent with a fundamental tension between the demands of research and the capacity of the community, similar to the tensions described by Boydell et al. (2016) in the context of arts-based health research (i.e., balancing structure vs. openness and flexibility; fulfilling academic obligations of truth and accuracy; resisting typical notions of what counts in academia; and managing expectations vis-à-vis measuring the impact). Tensions have been resolved through strong and respectful collaboration between community and academy. Through this protocol, we present a model of how effective research may be possible in Aboriginal communities, when driven by decision making at the community level. This paper reinforces the need for a redefinition of what is considered scientifically rigorous knowledge production when working with Aboriginal people. It is an example of a design that presents the opportunity for rapid uptake of results that lead to change in First Nations communities, because this design responds directly to local needs.

This research protocol is the result of respectful collaboration and meets the objectives and priorities of the community. This protocol is also in alignment with the Truth and Reconciliation Commission of Canada: Calls to Action report (TRC, 2015b). It aims to address inequities in health outcomes related to children’s emotional health. Regionally, this research is in line with the goals and plan of North East Local Health Integration Network’s (2016) Aboriginal Health Care Reconciliation Action Plan.

The overall impact of a process change (screening and triage) on health outcomes for children at risk will be clear in the future results from this study. Furthermore, the results are expected to impact intermediate determinants of health (Reading & Wien, 2009) and improve community health by enhancing the delivery of on-reserve health services. Finally, we hope that this paper may become one of many examples of how researchers may respond to the TRC Calls to Action, with research that puts the needs of Aboriginal children first through partnership, blended models, and real-world study designs.

References


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Adult Māori Patients’ Healthcare Experiences of the Emergency Department in a District Health Facility in New Zealand.

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Adult Māori Patients’ Healthcare Experiences of the Emergency Department in a District Health Facility in New Zealand.

Abstract
Globally, there are significant inequalities and disparities in health service delivery to Indigenous populations, including Māori in Aotearoa/New Zealand. This study explored the experiences of adult Māori patients in the emergency department (ED) of a district health facility in New Zealand. Qualitative research exploring the ED experiences of Māori patients is limited. Two semistructured interviews with 4 Māori participants were conducted, audio-recorded, transcribed, and thematically analysed with the help of the Māori health department within the hospital. The participants identified 3 main areas of improvements relating to (a) the ED environment, (b) the interactions with healthcare professionals (HCPs), and (c) the unique factors faced by the kaumātua (Māori elders). The main conclusions were that aspects of the ED environment, including the room layout and lack of privacy, could negatively influence Maori ED experiences. In addition, HCPs not adequately integrating the Māori view of health in their clinical practice also had a negative influence. The kaumātua faced unique challenges, including the language barrier and lack of sufficient information from HCPs during their patient journey. Educating HCPs and making the ED environment more sensitive to Māori could improve their experience.

Keywords
Māori, healthcare, emergency department, experiences, qualitative, interview, New Zealand

Glossary
karakia: traditional prayer
kaumātua: Māori elders
kaupapa Māori: Māori approach, principles or customary practice
manaakitanga: the way in which you receive, host, and care for visitors when they are with you
marae: traditional meeting place for Māori
mauri ora: healthy individuals
mihi: greeting, paying tribute
noa: the normal state of being
Te Reo Māori: Māori language
tikanga: correct procedure, protocol
wai ora: healthy environments
whakamā: shame or embarrassment
whakapapa: ancestry informing a person’s origin and identity
whakawhanaungatanga: the establishment of meaningful relationships
whānau: family
whānau ora: healthy families
whanaungatanga: a relationship, kinship, sense of family connection
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Introduction

Globally, Indigenous populations experience a greater burden of disease than non-Indigenous populations (Gracey & King, 2009; United Nations Inter-Agency Support Group on Indigenous Peoples’ Issues, 2014; Wilson & Barton, 2012). Māori experience this inequality and are more likely to have poorer health than their non-Māori counterparts, including a higher mortality from cardiovascular disease and a higher prevalence of respiratory disease, diabetes, and mental illness (Ministry of Health, 2015; Reid & Robson, 2006; Ring & Brown, 2003). The cause of this inequality is complex, owing to a variety of socioeconomic and lifestyle factors as well as racial discrimination and the impact of colonisation (Blakely, Tobias, & Atkinson, 2008; Ellison-Loschmann & Pearce, 2006; Harris et al., 2006; Reid & Robson, 2006; Wilson & Barton, 2012).

The Māori view of health is holistic and takes into account mental, emotional, familial, and spiritual wellbeing alongside physical health (Cram, Smith, & Johnstone, 2003; Durie, 2001; Rochford, 2004). Western medicine primarily focuses on physical health and therefore Māori patients may find this approach to healthcare lacking (Durie, 2001; McCreanor & Nairn, 2002). Ellison-Loschmann and Pearce (2006) and Reid and Robson (2006) suggest that good-quality healthcare for Māori occurs when healthcare is delivered in a culturally responsive manner. Māori healthcare professionals (HCPs) make up a small proportion of the workforce, and therefore non-Indigenous HCPs are more likely to care for Māori patients and may need specific training to deliver culturally appropriate care (Ratima et al., 2007; Wilson & Barton, 2012). Furthermore, the Treaty of Waitangi, a set of principles that empower and protect Māori people, guarantees their right to equal healthcare (Ellison-Loschmann & Pearce, 2006; Wilson & Barton, 2012). There are professional cultural competence standards and legislative requirements with regards to the treaty that HCPs need to adhere to if they are to maintain their practising certificates, including an active approach to integrating Māori health beliefs in medical practice, shared decision making between non-Māori and Māori people, and Māori autonomy and authority over their healthcare (Health Practitioners Competence Assurance Act, 2003; Nursing Council of New Zealand, 2005; Wilson & Barton, 2012). The Western construct of medicine provides little flexibility to accommodate alternative views of medicine, and hence the impact of colonisation may continue to hinder the inclusion of Māori health beliefs in current practice (Dodgson & Struthers, 2005).

Previous research on healthcare delivery has looked at the experiences of Māori patients in general practice, secondary care, cancer services, and psychiatric services (Dew et al., 2015; Johnstone & Read, 2000; McCreanor & Nairn, 2002; Wilson & Barton, 2012). Johnstone and Read (2000) and McCreanor and Nairn (2002) found that some general practitioners and psychiatrists displayed stereotypical thinking about Māori and made racist remarks. The emergency department (ED) is a different setting and may present unique challenges to the treatment of Māori. Managing acutely ill patients and triaging a large number of patients in ED can lead to quick judgements being made, increasing the risk of assuming stereotypes and hence negatively impacting the treatment of Indigenous people (Richardson, Babcock Irvin, & Tamayo-Sarver, 2003; van Ryn & Fu, 2003). Internationally, studies have shown that there are
ethnic inequalities within ED care, manifesting as Indigenous children having longer wait times and more Indigenous patients leaving ED before being seen, compared with their non-Indigenous counterparts (Park, Lee, & Epstein, 2009; Thomas & Anderson, 2006).

Studies examining Māori health experiences in the ED are sparse. The He Ritenga Whakaaro study looked into the experience of Māori patients in health services and provided some insight into ED care (Jansen, Bacal, & Crengle, 2008). They found that Māori experiences were largely influenced by the behaviour and attitude of the hospital staff and their interactions with them (Jansen et al., 2008). Further qualitative exploration of Māori ED health experiences appears to be needed, and this study plays a role in addressing this literature gap.

**Methods**

This study used a qualitative approach that applied semistructured interviews to examine Māori health experiences in ED. A list of all adult Māori patients presenting to ED in the 2 months prior to the interviews was obtained from the health facility. The criteria applied are summarised in Table 1.

**Table 1**

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
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<tbody>
<tr>
<td>Patients who were discharged from the emergency department after their visit.</td>
<td>Patients with mental illness.</td>
</tr>
<tr>
<td>Participants with ages from 25 to 50 years.</td>
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</table>

The district health board’s Māori health department stated that *kaumātua* may be less open to being interviewed from an outsider’s perspective, and hence the age range was set to 25 to 50 years.

Individuals meeting the above inclusion criteria were telephoned and those interested were sent information sheets via email or post. Those still interested confirmed an interview date. Interviews were conducted in the district health board’s Māori health department. Two female patients (aged between 30 and 40 years) volunteered and each brought a female guest with them (both over the age of 65), making the total number of study participants four. Though kaumātua were initially excluded in the recruitment of study participants, they were able to participate in the study because their presence was at the request of the recruited volunteers.

All four participants were offered the choice of English or Māori for the interviews and the presence of a Māori health representative. They were also provided with petrol/taxi vouchers to cover travel costs. Interviews were conducted in English and followed Māori Health Services tikanga/kawa protocols whereby the interviews were opened and closed with *karakia* and *whakawhanaungatanga* to provide an authentic and safe connection between the interviewer and participants. All participants
received refreshments as an act of manaakitanga. Refreshments also played a role in reinstating noa, to allow the participants to return to their normal activities.

**Data Collection**

Two semistructured interviews were conducted and audio-recorded with participants’ consent. The interviews used a mixture of open- and closed-ended questions to ensure key aspects of ED care were covered as well as giving the participants the opportunity to talk about Māori health issues more generally. The key questions explored the participants’ individual experiences in ED and what they felt could be improved in the future.

**Data Analysis**

The audio-recordings of the interviews were transcribed manually to preserve meaning. Māori phrases were translated with the help of the hospital’s Māori health department. Field notes were written during the interviews to provide additional context. The transcripts were examined to identify recurring themes and subthemes and these were manually tabulated to aid interpretation.

**Relationships**

Ethical approval was obtained from the district health board and the New Zealand Ministry of Health’s Health and Disability Ethics Committee. Participants received an information sheet with contact details prior to the study, and verbal and written consent were obtained before participation. Interviewees were asked if they wished to read the transcripts prior to data interpretation. Confidentiality was preserved by the removal of participant-identifying information from the transcripts. The recordings were destroyed following data transcription.

**Results**

The study had a total of four Māori participants, all of whom were female. Each interview had a female participant aged between 30 and 40 years and a second participant aged greater than 65 years. All participants highlighted the proactive nature of the nursing staff in the ED as well as the knowledgeable and often empowering approach of the doctors they encountered. The three main themes in the study (Table 2) relate to (a) the ED environment, (b) interactions with HCPs, and (c) unique factors for the kaumātua. The subthemes generated are discussed within these themes.

**Emergency Department Environment**

**Room layout.** The interaction between the layout of the ED environment and health was discussed, with participants stating that the layout directly affected their perception of their own health and wellbeing.

*It was the seating arrangement in ED. I found it really hostile. The seating is normally, like, all the chairs go against the walls so everyone can see one another but this particular*
day when I came in, all the seats were sort of like rows. And you could only go up on one side. And you had to sort of squish in and I didn’t like it because I found that I felt, like, claustrophobic. It was quite a hostile environment because you didn’t know who was behind you. I felt like I had to keep checking around me.

We’re aware of our surroundings. And I think all of those factors inform us about our wellbeing. Like all those little things. To the point of how we’re seated in the ED room. (Participant).

Table 2
A Summary of the Themes and Subthemes Generated from Data Analysis

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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</thead>
<tbody>
<tr>
<td>Emergency department environment</td>
<td>Room layout, Whānau presence</td>
</tr>
<tr>
<td></td>
<td>Spiritual assistance</td>
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<tr>
<td></td>
<td>Wait times</td>
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<td>Distinction between public and private spaces</td>
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<tr>
<td></td>
<td>Use of Te Reo Māori and pronunciation in emergency department</td>
</tr>
<tr>
<td>Interactions with healthcare professionals</td>
<td>Appreciation of Māori knowledge of their own body and health</td>
</tr>
<tr>
<td></td>
<td>Introductions</td>
</tr>
<tr>
<td></td>
<td>Continued Māori cultural training for healthcare professionals</td>
</tr>
<tr>
<td>Unique factors for the kaumatua</td>
<td></td>
</tr>
</tbody>
</table>

In this particular case, the patient registered a complaint with the hospital and it was dealt with and the seats were returned to their previous position. She also recounted an experience where the limited space in ED meant that she had to use chairs as a bed:

There were no beds left so they gave me chairs like this. They had no arms so they just grouped them together. And I had to wait for a few hours. I remember I had to lie down, but I laid down on the chairs. It’s chairs, because that’s where we put our bums. The idea of having to do that really made me feel quite sick. Having to lie on a chair and put my head on a chair. Was almost offensive, culturally. (Participant).

These examples show how the physical layout of a room can directly affect patients’ physical health and how comfortable they feel in the hospital environment.

Whānau presence. Whānau was identified as an important part of Māori health. Some interviewees acknowledged the limited space in ED meant there was little room for whānau, stating that
“whānau can wait,” and that sometimes whānau can make situations more stressful. Other interviewees stressed the importance of whānau in the healing process, making links to spirituality:

If they know that their mama or someone is there that they know, they’ll heal quicker!
Families when they have loved ones in here who are really sick, they’ll come in and do prayers (karakia). (Participant).

Furthermore, they discussed their frustration with the ED environment making it difficult to do this—for example, when faced with judgemental attitudes of some healthcare professionals towards their whānau.

I’ve always thought that they thought that we were taking up too many chairs. That should’ve been there for other people. People that are ill.
They think we’re a noisy lot. But our songs are prayers.
I’ve heard the nurses saying to them, “Oh, should’ve brought the whole tribe.” But it’s like our support because they’re all stressed. (Participant).

Spiritual assistance. Māori believe that spiritual health is a component of their health and wellbeing. The interviews portrayed different levels of spiritual need. In the first, spirituality was not a prominent factor: “Like a prayer if I’m sick? I do, but quietly to myself.” In the second interview, spirituality was more significant. One interviewee recounted the benefits of having a Māori cultural support person during one visit and believed it should be more readily offered in ED:

I think it will also encourage that, if they don’t want to take a religious side, then they can offer that support role for that person. And then engage with the family if there is a family for that person.
I think that could help reduce stress or reduce worry about the operation or whatever we’re facing is by offering them some kind of karakia (prayer) or some form of practice. And I think on the ED form when you sign in, I think it’s got something in there, if you want a chaplaincy. But I think it needs to be verbally made.
It could be from a small cultural practice like blessing the bed. You know when people die on the bed, well, we have a belief system that the residual of that person’s spirit can possible remain in that bed or in that room. I think it needs to be offered and talked about more in hospital/ED. Offer those services. But get clear on what you can offer to people.

Wait times. The interviewees mentioned dissatisfaction with the long waiting time in ED. However, they all believed that triaging was generally done fairly. They highlighted a particular problem with kaumātua waiting and their temptation to leave. Participants stressed that the kaumātua are heavily respected and hence, the idea of them waiting for a long time was more challenging to accept.
A friend of mine, she said her parents, were over 80, waited for 9 hours before the parents said, “It’s ok, we’re going to go home now.” (Participant).

Some nurse came out and shoved me in ED and then the doctor came and he goes, “Woah, you have to go to theatre straight away!” But I had been sitting in ED for 4 hours. Mind you, ED was full, I suppose they take the emergency ones first. Which is ok … but I had nearly walked out. And I said why don’t you just hurry up and do whatever you’re gonna do, do it! And get it over with or else I’ll go home. (Participant).

Distinction between public and private spaces. The busy environment of ED can lead to the blurring of public and private areas and elicit feelings of whakamā. Participants may feel overly exposed and distressed in public spaces. One interviewee reflected on an experience when her blood pressure and temperature were measured in the waiting room.

They used to take you to the side room. But now they don’t, they just do it all right there. There is no privacy whatsoever. I mean even if you try and whisper it’s still uncomfortable because there is another person right there waiting to sign up. (Participant).

Also, because not everyone is dressed appropriately for that too. You’re exposing yourself, your body parts. And you’re having to have that conversation in public. I don’t want everyone knowing my business. We’re quite private in that way. (Participant).

Use of Te Reo Māori and pronunciation in emergency department. Te Reo Māori is one of the official languages of New Zealand, the others being English and New Zealand Sign Language. The use of Te Reo Māori in ED was appreciated by one of the participants. Having the Māori word next to an English word felt more inclusive and gave a sense of ownership over their health system.

I like what they’ve got in ED what it says in English and then Māori underneath or Māori next to. Or like, how to wash your hands and they’ve got it written in Māori, I like that. Especially for the young kids growing up. You know, they understand. (Participant).

They (medical students) always ask my dad how do you say hello and goodbye. Things like that. They’re always asking, which is good. Keeps them interested in. So yeah, I’m happy with it. (Participant).

In addition, another participant highlighted the importance of names, recommending HCPs take an interest in Māori names as well as confirming the pronunciation in a polite way.
I think it would be nice if the doctor or the nurse or whoever tries or attempts it. And then checks with the person. I think is more respectful. (Participant).

Our names are really important to us. Because I’m named after [community name] where I come from and it’s a really special place. So I get a little bit peeved off when it’s not done properly. (Participant).

Te Reo Māori holds the narrative and knowledge to maintain the continuation of Māori cultural rights and practices, and therefore mispronouncing names, without effort to do otherwise, can be perceived as rude and as devaluing the individual involved.

**Interactions with Healthcare Professionals**

**Appreciation of Māori knowledge of their own body and health.** Having an awareness of one’s own body and health was mentioned in both interviews. One participant described it as Māori having an “innate connection” with themselves. Having this belief may lead to conflict with HCPs who have alternative ideas. Interviewees described experiences of conflicts like this outside the context of this hospital’s ED, with one interviewee stating, “I know my body and you don’t.”

*It should be natural for us to say—this is how my body is talking to me and how I actually feel, intuitively, and I know it to be this way. (Participant).*

An appreciation of this Māori belief can be conveyed by giving patients choice. One interviewee spoke of a good ED experience she had where she was informed about a range of treatment options and was told that she could ultimately decide.

*That was really good because they were thorough. And then they went away and then they came back and asked me what I had decided. Yeah, I didn’t feel pressured, because they gave me that option. (Participant).*

**Introductions.** The importance of adequate introductions was reiterated several times. This is the process of *mihi*, which is where the welcome is inclusive of *whanaungatanga*. One interviewee shared her dislike of having multiple people at her bedside. Her experience involved a lack of introduction from medical students as they entered her room, and she described feeling vulnerable as her privacy was being breached.

*There will be three or four of them coming in, you know, youngsters. But if they don’t ask, I tell them to go. They have to have respect, don’t they? Like I have to respect their kaupapa so they should respect me as a person too. (Participant).*
In addition, participants described the experience of being called by the doctor from the waiting room as sterile and sometimes disrespectful.

*They call the patient and then they start walking away from the patient already! They start walking towards the door. They don’t say who they are. ... It’s like you’re just a number.* (Participant).

The participants stated that they would be happy with some introduction and some explanation as to who the HCP was and what was about to happen. Furthermore, one participant asked if healthcare staff were allowed to shake hands.

*Everyone should shake hands! If I was a doctor, I would call them up and I would smile, I would wait for them to get as close as possible to me, and then I would introduce myself to the person, right there. Then I’d start walking with them.* (Participant).

It was clear that this first interaction played a significant role in setting the tone of the rest of the consultation. They explained that a warm introduction made them feel important and respected, especially after waiting for a long period of time. One participant stated that without this interaction, Māori people might be more inclined to hold back. The participants acknowledged that the time-pressured nature of ED makes it difficult to establish long introductions, so they stated that they would be happy with a “simple hello, my name is. And come with me.”

Furthermore, participants explained that introductions allowed them to engage with the HCP on a spiritual level. One interviewee used an analogy to explain the importance of introductions and handshakes. She compared the importance of understanding *whakapapa* with a stethoscope.

*The stethoscope informs the person about what’s going on. What they can hear. For Māori people, a handshake is a stethoscope for us. We are informed directly through spiritual link and an innate knowingness about who we’re talking with and what environment we’re in. It’s our expression of acknowledging the person that we’re with.* (Participant).

**Continued Māori cultural training for healthcare professionals.** Some interviewees recommended compulsory Māori cultural training for HCPs. They stated that regular engagement with Māori culture will help HCPs understand the Māori view of health and wellbeing and will help achieve better practice. They suggested spending time in a *marae* and witnessing what happens there.

*They should be exposed to that environment at least once a year. Get a see into why we do what we do. It will inform their practices, it really will.* (Participant).
Because you’re not just a doctor, you’re going to be a doctor that can engage with a cultural identity. And that means that even if you get the smallest glimpse of that, you have an opening to their world. That’s really huge! (Participant).

Unique Factors for the Kaumātua

The interviewees highlighted particular barriers that affect the kaumātua. One interviewee stated that her elderly father would wait until his medical condition was severe before presenting to ED. The waiting involved in ED may be a greater hindrance for kaumātua, discouraging them from seeking care. In addition, the act of doing medical observations, for example, blood pressure and temperature recording, publicly in the waiting room was perceived as even more offensive for kaumātua. The importance of sensitive care for elderly patients was further reiterated in the context of introductions.

Don’t call out to them and walk away. Some of them need actual physical assurance, they need the doctor to be still. They need to be clear from their body language. What’s not clear for Māori people is, and even worse for older people, is if you call their name and then you walk off. Because they don’t actually know what’s being said. (Participant).

One interviewee gave another example where an elderly person was unable to use their nebulizer after being given a written explanation by a HCP. The interviewees stated that elderly people would have a better grasp if they had visual tools or were shown how to use it.

Like a card with information on it, they’ll look at that and throw it away. Too much writing! Because the older people are a bit more visual. More hands on. (Participant).

Furthermore, language is more likely to be a barrier for kaumātua. One participant suggested that having a Māori cultural support person present and acting as an advocate might ease this situation.

Limitations

This study has a limited sample size of four participants and therefore the themes outlined should be cautiously applied to other settings. In addition, all the participants were women and therefore the themes identified may not be applicable to men. Whilst this study attempted to recruit men, it proved difficult. Finding ways to engage men in these types of studies is important to get a more diverse picture of Māori health experiences. Finally, being an interviewer from a different cultural background made it challenging to fully interpret Māori culture, although the collaboration with the hospital’s Māori health department made it easier to understand some concepts and ideas.

Discussion

Some of the themes in this study have been identified in previous literature. For example, the unfamiliarity of the hospital environment can be a source of great discomfort for Māori (Wilson &
Māori recognise the hospital environment they are entering is dominated by Western biomedical constructs of health and hence do not always cater to spiritual and mental healing (Wilson & Barton, 2012). Conflicts between these perspectives of health have been found in other studies (Dew et al., 2015). One participant with cancer voiced her distrust of the Western medical system as she found it to belittle Māori interpretations of health (Dew et al., 2015). This conflict seems to arise where there is perceived disregard for Māori views on health and a refusal to use a collaborative approach. An appreciation of the Māori worldview would be empowering and help facilitate mutual respect.

The importance of whānau has arisen on multiple occasions in literature and is believed to be an important aspect of health (Ministry of Health, 2014). It is perceived as a support base when someone is ill in ED (Dew et al., 2015; Jansen et al., 2008; Wilson & Barton, 2012). Reciting karakia together was seen as an important part of healing in cancer (Dew et al., 2015). Furthermore, Jansen et al. (2008) highlighted that having many members of whānau accompanying a patient often resulted in judgement and disrespect from some HCPs. Disrespect from HCPs could cause whakamā, a major barrier for Māori, and could lead to patients leaving hospital prematurely and hinder usage of healthcare in the future (Jansen et al., 2008; Walker et al., 2017; Wilson & Barton, 2012).

In addition, it is important to note that the significant presence of whānau may result in some tensions. For example, the study conducted by Dew et al. (2015) included a participant who stated that it is difficult to disagree with whānau. This corroborates a perspective found in this study when an interviewee stated that “whānau can wait” and that sometimes the worst people an individual can confide in are their whānau. Striking a balance between allowing whānau to be present in healthcare decision making and giving solely individualised patient care may be challenging and depends on the preference of a given individual, but it is important to acknowledge and respect that Māori patients may choose to operate as a familial unit (Dew et al., 2015; Walker et al., 2017).

Another theme that has been identified in literature is the disadvantage of long waiting times (Jansen et al., 2008). 2Hui participants stated that they were sometimes confused as to why they had to wait for such long periods of time and wished to know why that was and when they would be seen (Jansen et al., 2008). This may be challenging to address in ED; however, better communication in the waiting room may ease this dissatisfaction. For example, reception staff could provide more announcements with regards to waiting time and show compassion to those who are frustrated and prepared to leave. Better communication in this context also plays a role in protecting patient safety as it stops those who require urgent hospital care from leaving and prevents further deterioration of their physical health.

Inadequacy of introductions by HCPs has been cited as an issue in other studies (Jansen et al., 2008; Walker et al., 2017). One participant stated that they “went through the hospital system just like I was a box, or a letter with a stamp on” (Jansen et al., 2008, p. 50). This perspective resembled what an interviewee said in this study when she reflected on doctors calling her from the waiting room as if she
were just a number. Lack of personal acknowledgement is perceived as disrespectful and may hinder communication in the medical setting (Jansen et al., 2008; Walker et al., 2017). In addition, if participants felt they were not being listened to, they would “clam up” (Jansen et al., 2008, p. 52). In this study, the interviewees reiterated this, stating that they would hold back information if they felt the doctor did not have time for them and would not establish a meaningful connection, which is the backbone of the doctor-patient relationship (Jansen et al., 2008; Walker et al., 2017). Similar to this study, Dew et al. (2015) identified that the presence of medical students at a patient’s bedside without adequate introductions was disconcerting and evoked a feeling of whakamā.

One participant recounted his anger with a doctor entering his room with medical students and talking about him without his permission (Dew et al., 2015). Furthermore, breaching privacy in this manner can leave Māori patients feeling vulnerable. Another participant in the study by Dew et al. (2015) stated that she felt embarrassed having to discuss her medical needs in the reception area and felt it was an unnecessary breach of privacy. Comments regarding the lack of distinction between public and private spaces also emerged in our study. The importance of the environment is acknowledged in The Guide to He Korowai Oranga: Māori Health Strategy, which identifies the three elements of good health: healthy individuals (mauri ora), healthy families (whānau ora), and healthy environments (wai ora) (Ministry of Health, 2014). Wai ora highlights the impact of the external environment on health and wellbeing and states that an environment should be optimised to sustain healthy life. With this concept in mind, the ED environment may need to be adapted to ensure it feels safe.

Finally, the use of Māori language in ED was appreciated by one of the interviewees in this study when she stated that seeing the Māori word next to an English word felt more inclusive. Another study identified that an appreciation of Te Reo Māori (Māori language) should be encouraged in the medical setting (Pitama, Ahuriri-Driscoll, Huria, Lacey, & Robertson, 2011). The researchers found in general practice that patients would expect doctors to know or understand the words they were using or politely seek clarification. If doctors failed to acknowledge or show interest in Te Reo Māori, they would perceive this as the doctor not wanting to build a rapport with them, which led to them disengaging with the healthcare system for some time (Pitama et al., 2011).

In addition, Pitama et al. (2011) found that mispronunciation of names early on in a patient’s journey, for example in the reception area, led to patients feeling belittled or unwelcome in clinic later on. Therefore, an appreciation of Māori names and Te Reo Māori from the onset of the patient journey can prevent this potential barrier to healthcare access. As stated by participants in this study, if HCPs take an interest in Māori culture, the relationship between doctors and Māori patients may be strengthened. This is because Māori make connections with new people on the basis of understanding of an individual’s origin and identity (whakapapa), and doing so begins with adequate introductions and taking an interest in someone’s name.
Table 3 summarises our recommendations for ED staff based on our results.

Table 3
**Recommendations for Emergency Departments (EDs) Based on the Results from the Thematic Analysis**

<table>
<thead>
<tr>
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<th>Recommendation</th>
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<tbody>
<tr>
<td>1</td>
<td>Make proper introductions in ED, including a handshake.</td>
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<tr>
<td>2</td>
<td>With compassion, acknowledge long wait times and encourage patients to wait.</td>
</tr>
<tr>
<td>3</td>
<td>Ask a patient’s preference with regards to whānau being present in decision making.</td>
</tr>
<tr>
<td>4</td>
<td>Offer the service of a Māori cultural support person, especially for kaumātua.</td>
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<tr>
<td>5</td>
<td>Make the public and private spaces in ED more distinct and respect the privacy of individuals, particularly when doing medical observations.</td>
</tr>
<tr>
<td>6</td>
<td>Appreciate Māori intuition about their own body and health and encourage shared decision making.</td>
</tr>
<tr>
<td>7</td>
<td>Introduce compulsory Māori health training for healthcare professionals with annual refreshers.</td>
</tr>
<tr>
<td>8</td>
<td>Continue to incorporate Te Reo Māori in the medical setting, striving to pronounce Māori names correctly and checking pronunciation in a sensitive manner.</td>
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</table>

**Conclusion**

In conclusion, participants largely reported satisfaction with this district health facility’s ED, highlighting positives such as the proactive nature of nursing staff and the knowledgeable and empowering approach of doctors. This study has highlighted the impact of the ED environment and interactions with HCPs on Māori experiences and has found that special care must be taken when treating the kaumātua. Service provision is improved when the health system and HCPs recognise what is important to Māori people and take appropriate steps to widen their knowledge.

**References**


Barrier to Healthcare Access Faced by Indigenous Women in the Guatemalan Highland.

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Abstract
Utilizing the Framework Method, qualitative research determined the effects of potential barriers to healthcare access faced by 15 self-selected, consenting Indigenous women living in three different communities in the Guatemalan highlands. The women were actively involved in the nutritional recuperation program of the Community Organization, a non-profit clinic. Data collection involved recorded interviews based on a questionnaire designed to ensure culture competency. Responses were grouped into categories based on their relation to potential barriers to healthcare access and were then coded based on impacts on healthcare seeking behaviours. Intercoder reliability was measured and negotiated agreement of results was conducted to reach 100% agreement. Analyses of coded responses compared results between communities and between available sectors of healthcare (folk, public, and non-profit). Inductive reasoning was used to determine the effect of beliefs related to illness on healthcare seeking behaviour. Analyses showed significant differences in the impact of geographical barriers to healthcare access among communities across public and non-profit sectors of healthcare, $p < 0.05$, and demonstrated categorization of disease states and influence of beliefs related to illness on healthcare seeking behaviour. Results demonstrated a hierarchy of barriers, with barriers such as cost, perceived quality of care, trust of medical provider, and available time only showing a negative effect once the barrier of geography was overcome. Despite the sample bias, these results give insight into factors affecting healthcare seeking behaviours that could contribute to the low utilization of healthcare seen in this population.

Keywords
Healthcare Access, Indigenous Health, Maya, Qualitative Analysis, Cultural Beliefs.

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Glossary

Mal de ojo: Evil eye, illness affecting children when someone looks at them with a strong glance, causing an imbalance in their normal state of heat that is attributed to be the cause of a variety of symptoms including vomiting, diarrhea, crying, lack of appetite, lack of sleeping, fever, intestinal infection, and susto (fright). Natural remedies that can cure mal de ojo involve the use of rue, peppers, oil, passing an egg over the body, alcohol, or garlic.

Lombrices: Worms that are believed to exist in the stomach since birth. A variety of digestive disorders are attributed to the activation of these worms.

Chipe: Illness that occurs when a child becomes jealous or emotional when their mother is pregnant. Symptoms include crying and loss of appetite

Introduction

Compared with other countries in Latin America, Guatemala is among the most populated and the poorest (Bowser & Mahal, 2011). Guatemala experiences major health challenges, including high rates of malnutrition, infant mortality, and maternal mortality (World Health Organization, 2017). General trends in epidemiology in Guatemala include high incidence of infectious disease, malnutrition, malaria; increasing rates of infectious disease, malnutrition, AIDS, cardiovascular disease; and decreasing rates of pulmonary tuberculosis and communicable disease mortality (Gragnolati & Marini, 2003; Pan American Health Organization, 2007). Worsened health outcomes are seen in both rural and Indigenous populations. Infant mortality rates are higher in Guatemala than other countries in Latin America, with even higher rates among Indigenous populations in the highlands (Lang & Elkin, 1997). Rates of maternal mortality and chronic malnutrition are also higher among the Indigenous population in Guatemala (World Health Organization, 2017). The Indigenous people make up 41% of the total population in Guatemala, with 76% of the Indigenous population described as poor and 29% as extremely poor (Pan American Health Organization, 2007). Mayan residents of the rural highlands experience limited access to healthcare services with few available providers (Bhatt, 2012). Additionally, life expectancy at birth is three years lower for Mayan women compared to that of the general population of Guatemala (Schooley, Mundt, Wagner, Fullerton, & O’Donnell, 2009). It is evident that the health challenges faced by Guatemalans affect the Mayan population to a much greater extent.

The pluralist medical system in Guatemala provides a disjointed platform for confronting these poor health outcomes. The public sector, under supervision of the Guatemalan Ministerio de Salud Pública y Asistencia Social (Ministry of Health and Social Welfare) provides public health posts and health centers that are not commonly accessible for the Mayan population. The health posts that are accessible to the Indigenous population typically offer limited services and are under-staffed (Bhatt, 2012). The private sector is separated into non-profit and for-profit divisions. For-profit hospitals are located near cities and are expensive; non-profit clinics are not common and experience a shortage of resources due to the nature of being non-profit. Lastly, the folk sector includes traditional healers and lay people and are classified as curers, midwives, massage specialists, and spiritual healers (Bhatt, 2012). Midwives typically learn basic
skills from older relatives and do not receive formal training (Cooper & Yarbrough, 2010). Despite the variety of facilities, utilization of healthcare services is low (Annis, 1981; Bhatt, 2012). It is estimated that over 40% of the population does not have access to affordable adequate healthcare services, an issue common in Spanish speaking countries around the world (Nations, 2012). One potential reason for the poor health outcomes in Guatemalan Indigenous populations could be a lack of access to healthcare. The identification and quantification of barriers to healthcare access can help identify social determinants of health affecting the Indigenous communities in Guatemala.

**Potential Barriers**

**Geography.** One potential barrier is the physical distance separating these communities from healthcare. It has been documented that hospitals are typically located farther away from Mayan communities, leaving only traditional healers and lay people accessible to rural populations (Bhatt, 2012; Lang & Elkin, 1997). One study showed that people living more than 3.5 kilometers from a health post only accounted for 15% of those who visit the health post (Bhatt, 2012). Geography plays a role in limiting healthcare seeking behaviours, but since the majority of the Mayan highland population lives within five kilometers of a public health post it is apparent that other factors limit healthcare access (Annis, 1981).

**Lack of available time.** Lack of available time could deter individuals from healthcare seeking behaviours. This category of healthcare barrier considers the time it takes to travel to and wait at a medical center before receiving attention. The implications of which include not being able to work, care for children, or take care of the household (Grimes, Bowman, Dodgion, & Lavy, 2011; Lang & Elkin, 1997). Thus, available time is a reasonable deterrent to healthcare seeking behaviours across healthcare facilities.

**Trust in medical providers.** With respect to Indigenous populations, the trust in medical providers could limit healthcare access. These populations have experienced a history of oppression by the Ladino (mestizo) population that predominately makes up the professional and private healthcare sector (Bhatt, 2012; Quintana & Segura-Herrera, 2003). As described in a report prepared by the Pan American Health Organization, there exists a lack of cultural sensitivity in the practice of modern health workers (Hughes, 2004). These modern practices do not consider the holistic view of health held by many Indigenous people; this holistic view requires a balance of the mind, body, and spirit (Hughes, 2004). This history and perceived misunderstanding of cultural beliefs contribute to the mistrust that exists between Indigenous populations and healthcare professionals. Schooley et al. (2009) confirms the influence of trust in medical providers as researchers describe a woman’s decision to seek healthcare as determined by whether or not this care is perceived as safe, secure, and culturally appropriate (Schooley et al., 2009).

**Perceived quality of care.** It has been documented that poorly perceived quality of care is a deterrent of healthcare seeking behaviours. This issue is a common barrier to seeking obstetric care (Berry, 2008). It is important to note that the patient determines the quality of care, a practice that is different than in Western care standards. For this reason, differences in beliefs relating to illness and treatment could
contribute to perceived quality of care. The lack of medical equipment, trained staff, and medication also negatively influences the perceived quality of care in public health posts (Bhatt, 2012; Grimes et al., 2011). Thus it has been proposed that poorly perceived quality of care prevents healthcare seeking behaviours, particularly with respect to public health services.

Cost. As stated, 76% of the Indigenous population is described as poor, and 29% as extremely poor (Pan American Health Organization, 2007). As a result, cost of medical treatment is likely a large barrier to healthcare access. The small fee per visit at the government health posts is relatively high compared to family incomes (Bhatt, 2012). A larger issue associated with cost is not the provider fees but the high cost of medication (Bhatt, 2012). Other associated costs include the cost of transportation and loss of income (Grimes et al., 2011). Bhatt describes the care from traditional healers and public health posts as the only economically feasible healthcare options for the Maya (Bhatt, 2012). This evidence supports that cost is a deterring factor to healthcare access.

Machismo. The power imbalance between genders is widespread throughout the Mayan population (Bellino, 2009). This dynamic, characterized as machismo, often leads to verbal and physical abuse (Suarez & Jordan, 2007). It also acts as a barrier to healthcare access for women and children, since this imbalance grants males dominant authority over household decisions, including the spending of money on healthcare services (Carter, 2004; Schooley et al., 2009). As described by Hughes, the ability of a woman to reach a state of good health and quality of life is dependent on their relationship with men and the established gender roles (Hughes, 2004). Therefore, machismo could have act as a barrier to healthcare access for many Indigenous families.

Cultural Beliefs. Cultural beliefs relating to illness could deter healthcare seeking behaviours. Illness, as perceived by traditional Mayan beliefs, is a result of an imbalance of hot and cold in the body caused by a variety of factors (Hawkins, 2007; Messer, 1987). Traditional remedies to restore balance within the body include herbal cures, certain foods, or sweat baths (Bhatt, 2012). Although it has been stated that the use of traditional healers using these remedies is declining, the preference of these remedies influences healthcare seeking behaviours (Bhatt, 2012; Grimes et al., 2011). Thus, cultural beliefs relating to illness is another potential barrier to healthcare access.

Methods

Study Location

Research was conducted in three communities within the area the Community Organization serves.

Population

Five women from each community (Table 1), Community 1, Community 2, and Community 3, were self-identified. The purpose of this research was explained to each participant to help support clinic
development and improvement of programming and service delivery. Informed consent to participate prior to beginning the interview was provided verbally by each participant, with use of an approved oral consent script that detailed research proceedings. The participants volunteered for participation during Nutritional Recuperation Program meetings. All women involved in this program are Indigenous and Spanish speaking.

Table 1

Characteristics of Women Interviewed, Average of 25.1 Years with 2.7 Children.

<table>
<thead>
<tr>
<th>Community</th>
<th>Age</th>
<th>Marital Status</th>
<th>Occupation</th>
<th>Number of Living Children</th>
<th>Place of Childbirth</th>
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<tbody>
<tr>
<td>1</td>
<td>24</td>
<td>Not married</td>
<td>Homemaker</td>
<td>1</td>
<td>Hospital</td>
</tr>
<tr>
<td>1</td>
<td>24</td>
<td>Not married</td>
<td>Homemaker</td>
<td>3</td>
<td>Hospital</td>
</tr>
<tr>
<td>1</td>
<td>32</td>
<td>Not married</td>
<td>Homemaker</td>
<td>3</td>
<td>Hospital</td>
</tr>
<tr>
<td>1</td>
<td>23</td>
<td>Married</td>
<td>Homemaker</td>
<td>2</td>
<td>Hospital</td>
</tr>
<tr>
<td>1</td>
<td>19</td>
<td>Married</td>
<td>Homemaker</td>
<td>1</td>
<td>Hospital</td>
</tr>
<tr>
<td>2</td>
<td>19</td>
<td>Married</td>
<td>Homemaker</td>
<td>1</td>
<td>Hospital</td>
</tr>
<tr>
<td>2</td>
<td>27</td>
<td>Married</td>
<td>Homemaker</td>
<td>1</td>
<td>Hospital</td>
</tr>
<tr>
<td>2</td>
<td>45</td>
<td>Married</td>
<td>Homemaker</td>
<td>8</td>
<td>Temazcal</td>
</tr>
<tr>
<td>2</td>
<td>25</td>
<td>Married</td>
<td>Homemaker</td>
<td>5</td>
<td>Hospital (4), midwife (1)</td>
</tr>
<tr>
<td>2</td>
<td>27</td>
<td>Not married</td>
<td>Homemaker</td>
<td>1</td>
<td>Hospital</td>
</tr>
<tr>
<td>3</td>
<td>24</td>
<td>Married</td>
<td>Homemaker</td>
<td>3</td>
<td>Hospital</td>
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<tr>
<td>3</td>
<td>24</td>
<td>Married</td>
<td>Homemaker</td>
<td>4</td>
<td>Midwife</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
<td>Married</td>
<td>Sells flowers</td>
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<td>24</td>
<td>Married</td>
<td>Homemaker</td>
<td>2</td>
<td>Midwife</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
<td>Married</td>
<td>Homemaker</td>
<td>2</td>
<td>Hospital</td>
</tr>
</tbody>
</table>

Questionnaire Design

A review of the literature informed potential barriers later discussed in the interviews. Preliminary questions were created based on this research and were written to assess the effects of potential barriers in the different sectors of healthcare that exist in this region: the public sector, the non-profit sector, and the folk sector. These questions were translated to Spanish and edited with the help of clinic leaders to ensure cultural competency (see Appendix A).

Data Collection

The interviews were conducted in Spanish, recorded using a Zoom H4 Handy Recorder, and later transcribed and translated with the help of local community members to ensure that all recorded and transcribed responses were accurately documented.
Data Analysis

Qualitative data was analyzed based on the Framework Method previously established in the global health field (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The identified potential barriers functioned as categories, with participant responses coded based on the degree to which an identified barrier worked for or against health-seeking behaviours.

The responses were coded on a numerical scale of -2 to +2 based on whether or not the response represented a quality that would greatly prevent (-2) or promote (+2) seeking medical attention. The responses were analyzed for each community, in each sector of available healthcare. Two scorers analyzed data independently, and results were tested for intercoder reliability using appropriately established methods (Campbell, Quincy, Osserman, & Pedersen, 2013). One-way ANOVA was utilized to compare variation between communities. Inductive methods were used to identify categorization of disease states based on responses to questions concerning beliefs relating to illness.

Relationship

This research was conducted in coordination with University and the Community. Institutional protocols of University were followed, with the study design being approved by the Institutional Review Board at University, protocol number D0053. The Community Organization provides support to malnourished children and pregnant women by means of medical interventions and health education. This organization allowed access to the Indigenous communities.

Results

Initial analyses achieved 58% intercoder reliability, and negotiated agreement raised this to 100%. With respect to the categories of machismo and beliefs regarding illness, it became apparent that these factors influencing healthcare-seeking behaviours could not be analyzed according to this coding scheme, as they did not appropriately fit into categories. Machismo was not reported by the sample, and thus could not be assessed. Inductive reasoning was used to determine the effect of beliefs relating to illness. The numbers of scored responses for the effect of each of the remaining potential barrier to healthcare access per sector of healthcare, as well as guidelines for coding are summarized in Appendix B and C, respectively. The averages of all responses for each community are summarized in Table 2 and Figure 1. The averages of responses in each sector of healthcare, public, non-profit, and folk, are summarized Figures 2, 3, and 4 respectively. Within the public sector, the most negative barriers (i.e., those that impeded healthcare-seeking behaviours the most) were geography, cost, and available time. Within the non-profit sector, the most negative barriers were geography and available time. Lastly, within the folk sector, the only very negative barrier to healthcare access was found to be available time. Significant differences in the community average effects of geography and cost between sectors of healthcare were found, $p < 0.001$. Significant differences in the effect of geography between communities were demonstrated in the average responses for the public and non-profit sectors, $p < 0.01$. 
Table 2. Average Responses for Each Community per Category of Potential Barrier.

<table>
<thead>
<tr>
<th></th>
<th>Geography</th>
<th>Available time</th>
<th>Trust of provider</th>
<th>Perceived quality of care</th>
<th>Cost</th>
</tr>
</thead>
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<td></td>
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<td>Community 1</td>
<td>-1.20</td>
<td>-0.80</td>
<td>0.60</td>
<td>1.20</td>
<td>-1.00</td>
</tr>
<tr>
<td>Community 2</td>
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<td>0.60</td>
<td>0.60</td>
<td>-1.00</td>
</tr>
<tr>
<td>Community 3</td>
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<td>0.80</td>
<td>0.80</td>
<td>0</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td>-1.48</td>
<td>-0.53</td>
<td>0.67</td>
<td>0.87</td>
<td>-0.67</td>
</tr>
<tr>
<td><strong>Non-Profit Sector</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community 1</td>
<td>1.00</td>
<td>-0.80</td>
<td>1.00</td>
<td>1.20</td>
<td>1.40</td>
</tr>
<tr>
<td>Community 2</td>
<td>-1.00</td>
<td>-0.60</td>
<td>1.00</td>
<td>1.00</td>
<td>0.60</td>
</tr>
<tr>
<td>Community 3</td>
<td>-2.00</td>
<td>-0.20</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td>-0.67</td>
<td>-0.53</td>
<td>1.00</td>
<td>1.07</td>
<td>1.00</td>
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<td><strong>Folk Sector</strong></td>
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<td></td>
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<td>Community 1</td>
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<td>-0.80</td>
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<td>0.06</td>
<td>0.40</td>
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<tr>
<td>Community 2</td>
<td>0.60</td>
<td>-0.60</td>
<td>1.00</td>
<td>1.00</td>
<td>-0.40</td>
</tr>
<tr>
<td>Community 3</td>
<td>2.00</td>
<td>0.20</td>
<td>1.00</td>
<td>1.00</td>
<td>-0.60</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td>1.20</td>
<td>-0.53</td>
<td>0.87</td>
<td>0.87</td>
<td>-0.20</td>
</tr>
</tbody>
</table>

Figure 1. Graph showing the relative effects (rated by the scale shown on the Y axis) of the barriers to healthcare access that were assessed in each of the three sectors of healthcare available in the Community. Responses were averaged across the three communities that were studied. Significant differences in the community average effects of geography and cost between sectors of healthcare were found, $p < 0.001$. 

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Beliefs Related to Illness and Categorization of Disease States

With regards to the beliefs relating to illness, findings showed illness as belonging to one of three disease states: those that can be treated by the folk sector with natural remedies; more serious states that require attention by trained personnel outside of the folk sector; and chronic illnesses. These beliefs related to illness seemingly had a great affect on the healthcare seeking decisions.

Illnesses that could only be treated by the folk sector include mal de ojo, lombrices, and chipe. These were three illnesses that were identified as only being able to be cured by the folk sector of healthcare. More serious illnesses were recognized as needing treatment by the non-profit or public sector of healthcare. These included any illness that was not initially cured using the folk sector, childbirth when perceived to be dangerous or problematic, respiratory or cardiovascular problems, and malnutrition. Lastly, it was believed that some chronic illnesses could not cured by any sector of healthcare. These chronic issues included diabetes, ulcers, and cancer. It was unclear from the results whether or not it was thought impossible to treat and alleviate the symptoms of these illnesses, or impossible to cure them. Nevertheless, these chronic illnesses were perceived as limitations of all three sectors of healthcare.

Limitations

It is likely that other barriers negatively impact this population but were not represented in this study due to bias from the sample population. The sample of women interviewed was from a group of women participating in health programs of the Community Organization. For this reason, it is likely that machismo, trust of medical provider, and perceived quality of care may also contribute as barriers that limit access to adequate medical care, but this was unable to be demonstrated in this select sample population. Language barriers were not addressed in this study, as the population of the Community widely speaks and understands Spanish. However, approximately 40% of the population in Guatemala speaks one or more of the 23 recognized Amerindian languages (Central Intelligence Agency, 2017). Of those who speak an Amerindian language, Spanish is sometimes learned as a second language, but the dialects remain very different (A Glei & Goldman, 2000; Beckett & Pebley, 2003). Therefore, language barriers may also be a large problem associated with rural healthcare access in Guatemala.

Discussion

Comparison of Communities

It is important to consider the varying impacts of these barriers on the different communities. Within the public sector of healthcare, there were slight deviations between the three communities for each potential barrier to healthcare access (Figure 2). Geography was a significantly larger negative barrier to healthcare access for Community 3 ($p < .05$). Cost, which was found to have a negative effect in all three communities, was found to negatively impact Community 2 the most. On the other hand, Community 3 was impacted the least out of the three communities by cost.

Community differences were also identified within the non-profit sector (Figure 3). The effect of geography was widely varied among communities. Geography had significantly larger negative impact
in Community 3, a lesser, negative impact in Community 2, and a positive impact in Community 1 ($p < .05$). Cost promoted health-seeking behaviours in the non-profit sector but had less of a positive effect in Community 2 and a slightly more positive effect in Community 3.

**Figure 2.** Graph showing the relative effects (rated by the scale shown on the Y axis) of the barriers to healthcare access in the public sector of the healthcare system as assessed in each community and averaged across the three communities. Geography was a significantly larger negative barrier to healthcare access for Community 3 ($p < .05$).

**Figure 3.** Graph showing the relative effects (rated by the scale shown on the Y axis) of the potential barriers to healthcare access in the non-profit sector of the healthcare system as assessed in each
community. Geography had significantly larger negative impact in Community 3, a lesser, negative impact in Community 2, and a positive impact in Community 1 ($p < .05$).

Variance in the relative effects of the identified potential barriers was also found within the folk sector of healthcare (Figure 4). With regards to geography, this promoted healthcare seeking behaviours in all three communities and had the slightly greater positive effect in Community 3. Available time affected each community differently. It had a slightly positive effect in Community 3, a slightly negative effect in Community 2, and a slightly more negative effect in Community 1. The effect of cost varied between the three communities. Cost of the folk sector hampered health seeking behaviours in Community 3, had no effect in Community 2, and promoted these behaviours in Community 1.

The differences in relative effects of barriers to healthcare access are important to note as it shows the need for individual community assessments. Analysis of these differences sheds light on a hierarchy of barriers that exist within the communities. For example, in Community 3 it is clear that the largest and most prominent barrier to the public and non-profit sectors of healthcare is geography. In the communities of Community 1 and Community 2, we begin to see the negative effect of barriers such as cost of the public sector. It is likely that cost only becomes a barrier to healthcare access once the barrier of geography is overcome. It could be important to identify the hierarchy of barriers in order to target interventions to address the most important barriers and maximize effectiveness.
Conclusion

Ultimately it seems as though the folk sector is the most widely used among the communities. This could be due to the close proximity of community healers and midwives or to the beliefs that many illnesses can only be treated by this sector. This exemplifies the importance of culturally competent care as well as community involvement in medical education, training, and practice. This could involve working with healers and midwives. This sort of integration between westernized, modern medical practices and traditional, folk practices could be integral in expanding access to adequate healthcare in this region.

This preliminary report on barriers to healthcare access gives a small glimpse into some of the challenges that face the Community. Analysis of factors that influence healthcare seeking behaviour can help to explain why healthcare utilization is low in this population. In order to expand on this research, it would be beneficial to increase the sample size and interview a more diverse population. Additionally, it would be beneficial to conduct a more in-depth research study on the cultural beliefs of the community. This would allow for a better understanding of the illnesses that are perceived to only be able to be cured by the folk sector and improved cultural competency in medical practice. This method of identifying and ranking barriers to healthcare access seems to be an effective way to understand the root of health inequity and can be applied to improve healthcare interventions.

References


Appendices

Appendix A

Questionnaire Guidelines (translated into English)

The following questions were used to prompt a discussion relating to each topic outlined below:

1. Background questions:
   a. How old are you?
   b. Where do you live?
   c. How many children do you have?
   d. Are you married?
   e. Do you have a job?
   f. What do you do during a typical day?

2. Questions relating to the effect of geography:
   a. How far away is the nearest public hospital?
   b. How far away is Community Organization?
   c. Is there a midwife or community healer in your community?
   d. How long does it take to get to the public hospital?
   e. How long does it take to get to Community Organization?
   f. How long does it take to go to a community healer?

3. Questions relating to the effect of available time:
   a. If you or a family member became ill, would you have time to go to seek medical attention?
   b. Is the time it takes to get help at the hospital/Community Organization/with a community healer an obstacle that prevents you from seeking medical help when needed?

4. Questions relating to the effect of trust of medical provider:
   a. What do you think of public hospitals?
   b. Do you trust the people who work at the hospital?
   c. Do you agree with the practices at the hospital?
   d. What do you think of Community Organization?
   e. Do you trust the people who work at Community Organization?
   f. Do you agree with the practices of Community Organization?
   g. What do you think of the community healer and the midwife?
   h. Do you trust these people?
   i. Do you agree with their practices?

5. Questions relating to the effect of perceived quality of care:
   a. Do you think that hospitals provide effective medical care?
b. If you went to the hospital when you were sick, would you get better?
c. How does the hospital help you?
d. Do you think that Community Organization provides effective medical care?
e. If you went to the Community Organization when you were sick, would you get better?
f. How does Community Organization help you?
g. Do you think that the community healers and midwives provide effective medical care?
h. If you went to a community healer when you were sick, would you get better?
i. How does the community healer help you?

6. Questions relating to the effect of cost:
   a. Are the medical services at the hospital expensive?
   b. Are the medications at the hospital expensive?
   c. Are the medical services at Community Organization expensive?
   d. Are the medications at Community Organization expensive?
   e. Are the medical services of a community healer or a midwife expensive?
   f. Are the medications or remedies of the community healers or midwives expensive?

7. Questions relating to cultural beliefs surrounding health and sickness:
   a. Are there some illnesses that cannot be cured in the hospital? What are these? How do you treat them? What are their symptoms?
   b. Are there some illnesses that cannot be cured in Community Organization? What are these? How do you treat them? What are their symptoms?
   c. Are there some illnesses that cannot be cured with a community healer? What are these? How do you treat them? What are their symptoms?
   d. Are there some instances when a midwife cannot help you?

8. Questions relating to the effect of machismo:
   a. Do you tell your husband when you or your child is sick?
   b. Does your husband go with you to seek medical attention?
   c. Does your husband ever stop you from seeking medical attention?
### Appendix B

#### Table 3

**Number of Responses to the Effect of Geography per Community**

<table>
<thead>
<tr>
<th>Public Sector</th>
<th>Score</th>
<th>Community 1</th>
<th>Community 2</th>
<th>Community 3</th>
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<td>-2</td>
<td>1</td>
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<table>
<thead>
<tr>
<th>Non-profit Sector</th>
<th>Score</th>
<th>Community 1</th>
<th>Community 2</th>
<th>Community 3</th>
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### Table 4

**Number of Responses to the Effect of Available Time per Community**

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Table 5  
*Number of Responses to the Effect of Trust of Medical Provider per Community*

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Table 6  
*Number of Responses to the Effect of Perceived Quality of Care per Community*

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Table 7

*Number of Responses to the Effect of Cost per Community*

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Appendix C

Table 8

*Description of Coding Based on Responses Used in Data Analysis*

<table>
<thead>
<tr>
<th>Geography</th>
<th>Free time</th>
<th>Trust</th>
<th>Perceived quality</th>
<th>Cost</th>
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<tbody>
<tr>
<td>-2</td>
<td>Over 1 hour travel time</td>
<td>Great negative effect</td>
<td>Great limitation of trust</td>
<td>Always unaffordable</td>
</tr>
<tr>
<td>-1</td>
<td>Between 30 minutes to an hour</td>
<td>Some negative effect</td>
<td>Any doubt in trust of limitations of trust</td>
<td>Considered to have limitations or weakness in some way</td>
</tr>
<tr>
<td>0</td>
<td>Travel time depends on situation, answer was unclear</td>
<td>No effect</td>
<td>Uncertainty</td>
<td>Average</td>
</tr>
<tr>
<td>1</td>
<td>Between 15 and 30 minutes</td>
<td>Positive effect</td>
<td>Basic trust</td>
<td>Considered good</td>
</tr>
<tr>
<td>2</td>
<td>Under 15 minutes</td>
<td>Great positive effect</td>
<td>Great trust</td>
<td>Considered the best or great</td>
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August 2018

Caregivers’ Perspectives on the Determinants of Dietary Decisions in Six First Nation Communities.

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Caregivers’ Perspectives on the Determinants of Dietary Decisions in Six First Nation Communities.

Abstract
Colonialism is a fundamental determinant of Indigenous people’s health in Canada, yet little is known about its effects on food systems and dietary decisions in First Nation communities. A socioecological approach was used to explore the determinants of dietary decisions made by Indigenous caregivers. Conclusions are drawn from a narrative analysis of eight focus groups involving 33 caregivers in six First Nation communities. Caregivers identified the changes that they have observed in how food is procured, distributed, processed and prepared, along with the nutritional consequences and the sociocultural meanings of these changes. Determinants such as participation in the wage economy, low income, hunting and fishing regulations, availability of fish and game, and the proliferation of inexpensive, processed foods have altered the food systems and influenced dietary decisions made by caregivers in six First Nation communities. Initiatives such as community gardens, community freezers and community hunting camps are ways that these communities are seeking to regain food sovereignty.

Keywords
Indigenous health, nutrition, socioecological approach, determinants of health, colonialism
Introduction

Poor nutrition has been identified as a barrier to good health among Indigenous children in Canada. Dietary gaps such as not meeting recommendations for daily consumption of fruits and vegetables are critical examples of this issue (Earle, 2011). Obesity and other health outcomes such as anemia, dental caries, heart disease and diabetes have also been linked to poor nutrition among Indigenous populations (Willows, 2005). Poor nutrition is a result of dietary decisions which are influenced by a complex social and political environment. Dietary decisions are made by individuals but need to be considered within a food system. A food system refers to the processes that affect how food is acquired and processed as well as the socio-cultural meanings surrounding food (Willows, 2005). Understanding the determinants that influence food systems in First Nation communities is essential to addressing poor nutrition and preventing negative health outcomes. In this paper we draw from a socioecological approach (Willows, Hanley & Delormier, 2012) that reflects the insights of 33 caregiver participants. Focus groups were conducted to understand how food systems in six rural First Nation communities have changed and to identify the determinants that influence dietary decisions.

Food Systems and Indigenous Peoples

Indigenous peoples are the fastest growing population in Canada. In 2006, about one-third of this population was under the age of 15 (Statistics Canada, 2008). This young and rapidly growing population is perhaps the first generation of Indigenous peoples who have not relied on traditional foods as an integral component of their diet. Kuhnlein (2005) defined traditional foods as, “those foods that Indigenous Peoples have access to locally, without having to purchase them” (p. 3) while market foods are, “those foods that enter communities often through global industrially sponsored retail outlets, and which must be purchased (e.g. sugar, oil)” (p. 4).

Food is an important way of expressing culture through the methods used to acquire it, the values around how it is distributed and the ways in which it is prepared (Willows, 2005). Food is also linked to the maintenance of social relationships and is important to cultural identity. Willows (2005) states that, “the consumption of traditional foods is more than just about eating; it is the endpoint of a series of culturally meaningful processes…” (p. s33). Traditional food systems have been recognized as being significant for the holistic health of individuals and communities (Kuhnlein, 2009).

Food systems in First Nation communities have been disrupted by colonial policies. For example, in the 1880’s, government agents would limit rations as a way of punishing First Nation communities or to coerce Indigenous leaders into signing treaties so their people would not starve (Dickason & McNab, 2009). Access to traditional foods was compromised over generations through the loss of traditional lands. Indigenous peoples were discouraged from their traditional ways of obtaining food such as

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9 The term ‘Indian reserve’ has been rejected and communities have renamed themselves as First Nations to reflect their position as the first inhabitants of North America (NAHO, n.d.).
hunting and gathering and encouraged to take up farming (Dickason & McNab, 2009). This was particularly challenging in areas where the land was not suitable for agriculture. However, when Indigenous people were able to farm the land successfully the government would introduce regulations making it difficult to sell their produce or to invest in new technology (Dickason & McNab, 2009). At present, hunting and fishing regulations limit access to traditional foods through the requirements of costly licensing and enforcement.

The Indian residential school system disrupted family learned processes of preparing foods that had been handed down for generations (Willows et al., 2012). Residential school survivors have reported on the limited amount of food and the poor quality of food available to them as students (Truth and Reconciliation Commission of Canada, 2012). Students were expected to work in the gardens but often times were not allowed to partake in the fruits of their labour (Truth and Reconciliation Commission of Canada [TRC], 2012). Hunger was rampant and students often had to resort to stealing food in order to survive (TRC, 2012). Students longed for their traditional foods, but instead were fed unfamiliar foods such as pasta and processed meat (TRC, 2012). Dismal conditions at many residential schools were viewed as an opportunity to study the effects of malnutrition and to “assess the adaptability of a diet that was making its supposedly inevitable transition from ‘traditional’ to ‘modern’” (Mosby, 2013, p. 161).

These ongoing assaults on Indigenous food systems over generations have resulted in a transition from a traditional diet that was high in omega-3 fatty acids, low in carbohydrates, and rich in micronutrients, to a diet of market foods which is high in trans-fatty acids and carbohydrates, and low in nutrients (Earle, 2011; Willows, 2005). Understanding the impact of this transition on dietary decisions made by caregivers in six First Nation communities is the focus of this paper.

Methods

The research described in this paper contributes to a larger mixed-methods study seeking to understand health behaviours and obesity among Indigenous children in six First Nation communities. Community consent for this study was granted by all six First Nation band councils and ethics approval was obtained from the university Research Ethics Board. This topic was identified by Elders, health care workers and teachers within this region as a health priority. This paper reports on the perspectives of caregivers about the dietary decisions made in their households.

Data Collection

Participants in this study were mainly caregivers (i.e., parents or grandparents) of First Nation children and interested community members. Participants were invited through fliers that were sent home with students in the First Nation schools and through posters in the community. In the communities that did not have an elementary school, parents and guardians were mailed an invitation to participate.
Focus groups took place either at the community health center or in First Nation schools. Written consent to participate, and oral consent for audio-recording, was obtained prior to the start of the focus groups. Semi-structured and open-ended questions focused mainly on how and why nutrition has changed from the past to the present. All focus groups were conducted in English, and lasted between 90 and 120 minutes. A total of 33 caregivers participated in the focus groups (23 mothers, 4 fathers, and 6 grandparents or guardians). Most participants were women \( (n = 28) \).

Analysis

The focus groups were facilitated by the lead author, an Indigenous doctoral student and a member of one of the participating First Nation communities, thus giving the author an insider perspective along with particular biases. Given the personal, professional and educational background, the lead author has a dual perspective or what has been described as ‘two-eyed seeing’ (Bartlett, Marshall, & Marshall, 2012). This refers to understanding the world from both an Indigenous and a Western perspective. The lead author was supported by both Indigenous and Western scholars with extensive research experience in children’s health and First Nation communities.

This paper draws from a narrative analysis of focus groups with 33 caregivers of Indigenous children in six First Nation communities. Audio-recordings from the focus groups were transcribed and then imported into NVivo 10. The transcripts were reviewed for both surface level content, as well as underlying meanings (Babbie, 1992). Segments of data were coded with a label that categorized and summarized the data (Charmaz, 2006). Two member-checking sessions with some of the participants were held to solicit insight into the findings. Further analysis involved labelling and sorting the data into themes and sub-themes around the determinants that influenced the dietary decisions of participants.

Results

Dietary decisions were found to be influenced by interpersonal, community, and societal level factors as well as historical influences. In this study it was important to hear the voices of the participants who articulated their perceptions around food and nutrition. There were extensive discussions about how food has been procured, contrasting food from the land with market food from the grocery store. Food distribution was affected by the availability of game and fish, high costs, food quality, and transportation challenges. The processing and preparation of food is influenced by time, skills, availability of processed foods, and personal preferences. The health consequences of consuming certain types of food were of concern to the caregivers. Finally, participants referred to sociocultural beliefs around identity, feeling ‘lazy’, and the value of sharing.

Food from the Land

Participants recalled a time when they relied on ‘food from the land’ for a substantial portion of their diet as illustrated by this comment: “It was more off the land – land-based type food. And we went with the seasons. Whatever was growing we picked and we ate.” Land-based food includes wild game,
Hunting and Fishing

Hunting and fishing remain culturally significant activities in all participating communities. Participants reported that large game like moose and deer continued to be widely available, however small game such as rabbit and partridge, are scarce. Participants also reported that the indigenous fish stock has drastically declined limiting consumption. Due to limited access to certain types of game and fish, some participants reported that they only eat them at feasts. One of the participants commented on the availability of freshwater fish, “I think there’s fewer fish out there. When we used to go fishing we used to catch a lot of fish” (Sally, participant). As small game and fish are scarce, participants noted that it took longer to acquire them resulting in a focus on large game like deer and moose. Government regulations also limit when and where hunting and fishing activities can take place. Although there are treaty rights to hunt and fish, these practices continue to be infringed upon. An example of this occurred in a sting operation conducted by the Ontario Ministry of Natural Resources when their agents entrapped Indigenous hunters into selling wild game (DiGangi, 1993). This approach to fish and wildlife enforcement by the government was noted by one of the focus group participants:

They got so much regulation now that they govern, that they want to make sure that they got you. If you can live independently, then they can’t govern you. Live off the grid. They make sure, they could take your licence away, they could take a lot of things. The government’s got a hold of people now. (Ryan, participant).

Harvesting

Participants recalled picking different types of berries for personal consumption or to supplement their income. In the spring families would make maple syrup and apples were picked in the fall apples. Preserves, like jams and pickles, would be made from the foods they harvested, “My mom was a gatherer. She’d pick raspberries, strawberries, you name it. She got wild plums. She’d make jam out of it, for the winter. All that stuff, even acorns. We saved those too, eh” (Brian, participant). Participants also noted that harvesting fruit has declined in recent years.

Gardening

Gardening used to be a seasonal activity in these communities. Participants reported that most families had gardens that would supply them with fresh vegetables during the summer months and root vegetables that could be stored for the winter months. One participant stated,

We had a huge garden. I remember weeding and being part of that because we all had to take turns and do our share of it. So we had corn, potatoes, beans,
turnips ... those kinds of things. Carrots in the garden. My mom did canning.
(Addy, participant).

Participants reported that there were fewer households with gardens in their community.

**Raising Livestock**

Participants recalled that livestock like chickens, horses, and cows used to be raised in the communities but not many community members do this anymore. One participant noted, “And my mom, she took care of the chickens and made sure we got our eggs. And we had a cow. That’s where we got our milk” (Brian, participant). Traditional methods of procuring food from the land were labour intensive and activities like hunting, fishing, harvesting and raising livestock involved all family members.

**Food from the Grocery Store**

The shift from land-based food to the grocery store has resulted in significant changes to diets. Grocery stores are between five and 52 kilometres away from these communities with mostly processed foods available in convenience stores within the communities. Participants described the high cost, but poor quality, of fruits and vegetables in their communities, as well as transportation barriers to obtaining food from grocery stores in towns.

**Shopping at a Grocery Store**

Participants reported that in the past their families only went to the grocery store once or twice per month and that the foods purchased were generally staples like flour and sugar and other ingredients to prepare meals from scratch. A participant stated, “What I remember is that it was things – like we did very little grocery shopping. So, you know, things that came in a can, a bag of sugar, flour, and stuff” (Addy, participant). In comparison, participants reported that they make more visits to the grocery store where mainly processed foods are purchased. This practice is a significant shift from the past when people relied mainly on whole foods from the land.

**Cost**

Market food in rural Ontario is expensive. This was an important consideration in food selection for participants, some of whom had limited incomes and had to ensure that the food they purchased was going to last the entire month. Participants noted difficulties in budgeting in order to afford nutritious foods, “I try to stretch my money as far as I can but still be nutritious” (Sandra, participant). Similarly, other participants noted that the cost of fresh foods is high compared to the amount of food that can be purchased, “You don’t get too much for your money now. $200 worth of groceries doesn’t get you much” (Josephine, participant). The high cost of food from grocery stores in rural Ontario affected food purchases with some participants who perceived convenience foods to be less expensive than whole foods.
Food Quality

Participants commented on the quality of the fruits and vegetables available in the grocery stores. They recalled instances of fruits and vegetables spoiling quickly. One participant noted, “The stuff we buy [in town] like for me I find if I buy fresh fruit at [the grocery store] and two days later it’s like mouldy” (Louise, participant). Other participants supported this as well:

- The amount of time we go to get fresh fruits and vegetables. Half the time the lettuce will wilt. So it’s basically the shelf life of fresh fruits and vegetables.
- Sometimes we go for a two-week span then we go get fresh stuff. (Alannah, participant).

Compounding the problem of poor quality fruits and vegetable in grocery stores is that the foods typically available for sale in the communities are in convenience stores and tend to be snack foods like chips or non-perishable food items.

Transportation

As there is no public transportation available in these communities, those families who do not have a vehicle find that much of their income can be spent on transportation. Because of the high cost of transportation, they made fewer trips to the grocery store requiring the food they purchased to last longer. This limited the purchase of fresh fruits and vegetables, and increased the purchase of shelf stable foods which do not spoil as quickly, but are typically nutrient deficient and/or high in sugar, fat, and salt. A participant reported that transportation is an important factor in access to fresh food:

- Cost you twenty bucks just to get to town. Hard to get around to those good vegetables right off the shelf. It just doesn’t happen. I get to town maybe once a week if that. So yeah, transportation is a big thing. (Kristan, participant).

Food procurement in the participating communities has transitioned from the land to the grocery store placing community members at risk for food insecurity. Food insecurity is not only impacted by the availability of game and fish but also the cost and quality of food, socioeconomic status and transportation costs.

Processing and Preparation of Food

The way in which food is processed and prepared influences the nutritional quality of the food. In addition, the type of food that is prepared is often based on food preferences. Participants reported that in the past, meals were prepared from ‘scratch’, that is, prepared at home, however now there is a greater reliance on processed foods. This marks a shift from meals made from whole foods, to meals prepared with some or all processed food.
Cooking From ‘Scratch’

As noted, participants reported that in the past, meals that were made ‘from scratch’ at home used whole food ingredients. These meals tended to be simple meals, such as a serving of meat and potatoes, with other root vegetables (i.e., carrots or turnips) may also be served. Wheat-based products such as bread or cake were also prepared at home. One participant recalled observing this process from their parent:

Well as a kid I remember my mom making everything from scratch like there was roast, there was always potatoes and a vegetable. And now I don’t do that so much. I probably do it maybe four days out of the week. Not consecutively.
Once in a while I like to keep it balanced and throw, like, French fries or some processed food [laughs]. (Sally, participant).

Some participants reported not having the cooking skills to prepare meals from ‘scratch’. Other participants recognized that they should eat more vegetables, but do not have the cooking skills required in order to prepare them. Participants also reported having wild game in their freezer but not knowing how to prepare it:

Like I think we have moose that somebody gave us, from in the winter and, but it’s just sitting in our fridge because I don’t really know how to cook it. And I know if I try it’s going to be awful. (Kristan, participant)

Convenience of Processed Foods

Participants noted that there has been a transition from meals prepared from whole foods to meals that are a combination of home cooked and processed foods. Some participants preferred processed foods because they don’t take as long to prepare. Processed foods, such as frozen pizza, can be heated up quickly, “Not too much wild. Ready-made, throw it in the oven and it’s done. Open the box and throw it in there. Chicken fingers and stuff. Fries, hamburgers already made” (Paula, participant).

Personal Preferences

Participants reported that food choices were made in consideration of their own preferences, and those of children who were ‘picky eaters’. In some families, the high cost of food was a deterrent to preparing food that their family does not like. Some participants indicated that they did not like eating wild game or fish because they either had too much when they were young, or were not exposed to it at all and had never acquired a taste for it, “My dad never liked wild meat when we were growing up so we never had it. That’s why we were always grocery store people. He wasn’t an eater that way so I don’t care for it myself now” (Alannah, participant). Similarly, other participants stated they had not grown into eating some foods, “Fish – but I never ate fish. I just could never acquire a taste for it” (Emily,
participant). In regards to preparing meals for children, one participant noted a need for accommodating their child’s tastes:

\textit{Especially, too, since it’s just me and my son at home. We’re both picky eaters, too. Gotta cook what he likes to eat because he doesn’t like that deer meat stuff like everyday kind of thing. I gotta cook to his likings, too. (Kristan, participant).}

The processing and preparation of food in these First Nation communities has undergone a significant transition. In the past, most food would be acquired from the land and prepared at home, however at present, most food is purchased and reheated rather than cooked. Cooking skills have declined, and participants reported that they do not have time to prepare meals from scratch. Food preferences can be seen as individual choice, however, there is evidence that highly processed foods that are high in fat, sugar, and salt are engineered to be appealing (Moss, 2013).

**Nutritional Consequences**

Participants in these focus groups demonstrated that they were knowledgeable about healthy foods by giving examples of meals they had prepared. They also recognized the connection between a poor diet and the risk of developing obesity and diabetes.

**Knowledge About Healthy Foods**

Responses from participants indicate that they were knowledgeable about healthy foods:

\textit{And me, myself being, I like to cook. I eat everything fresh as I possibly can, like without adding like cans and all that stuff, like, I cut all that stuff off. MSG, anything. Like, I cut all that stuff off. I just keep it right down to the basics. (Dexter, participant).}

Another participant reported also cooking healthy foods for meals, “I basically cook meat, potatoes, vegetables occasionally rice, pasta. Just fruits and vegetables at home” (Alannah, participant).

**Health Concerns**

Participants expressed concern about negative health outcomes related to poor food choices. One participant reported the impact that diabetes had in families grocery choices and concerns for the family’s health,

\textit{We used to, sometimes too, we didn’t have food to eat and we mostly ate scone, corn soup. I bet you that’s where all the diabetes came from eating salt pork, stuff like that, eh. Because sometimes, you know there was no, like grocery
stores or we didn’t have fridges to keep meat, fresh meat all the time. So I think that’s where the diabetes stepped in is when we started eating these kinds of foods eh. Like lot of fried, fried bread, you know scone. Salt pork, I remember eating a lot of salt pork when I was young. (Bernadette, participant).

Attempting to influence children to eat healthy and balanced meals to avoid the development of diabetes was also noted by other participants, “We’ve started pushing the vegetables on the boys and eating healthy. That’s a change for our whole household. That’s to prevent diabetes and get them into the habit of it” (Alannah, participant). Similarly, participants noted that they attempted to limit consumption of soda drinks due to familial concerns with diabetes in family units, “I always tell him, no, don’t buy pop because of diabetes. It runs in our family” (Kristan, participant).

Sociocultural Meanings

Acquiring food, selecting what to eat, and preparing food is a complex activity charged with sociocultural meanings. During the focus groups, participants discussed the importance of traditional foods for ceremonies, and how eating traditional foods are important to their Indigenous identity. In addition to not having the cooking skills and preferring processed foods, they also described themselves as too ‘lazy’ to cook food from ‘scratch’. In addition, personal finances have put constraints on the value of sharing.

Ceremonial

Traditional foods like wild game were seen as important for ceremonies like feasts, and described as holding special meaning for participants,

… my mom will can venison and so sometimes the only time we’ll eat like that, like the older foods is if we’re at a feast at my mom’s house or, and then again, she won’t make venison stew on a Tuesday. It’s almost something special now like you have it after a sweat lodge or something. She’ll have venison or like that kind of meat. But I wouldn’t make it on like a Wednesday. It’s like a special thing for me now. (Sandra, participant).

Often, these traditional foods are reserved for special occasions like feasts or ceremonies due to the skill and time required to prepare such foods.

Identity

Eating traditional foods such as wild game was seen as important to cultural identity: 

So every once in a while I don’t mind some game meat or stuff like that just for you know, a change of scenery or a change of diet or what not. But we don’t, we don’t eat as much as we probably should, as Indians. (Rodney, participant).
‘Lazy’

Some participants described themselves as ‘lazy’ when they relied on convenience foods for meals. One participant explained,

*It’s just that after a day at work then you get home and it’s like, ugh, I don’t feel like doing the whole food prep of doing a big meal so I throw a pizza in the oven or we’ll order a pizza whatever the case may be. But there’s nights where I... same thing that lazy mode like, ugh [laughter].* (Sally, participant).

When probed, two reasons were given for describing themselves in this way: firstly, participants reported feeling tired upon arrival home, and secondly, noted they felt they did not have sufficient time required to cook a meal from scratch.

Sharing in Times of Acarcity and Abundance

Sharing is noted as a fundamental value within this Indigenous group (Power, 2008). Historically, when food from the land was more abundant, participants reported that people would share food more readily within communities. As food from the land has become scarce, the value of sharing has been eroded over time. Even though these First Nation communities have improved socioeconomically, some participants described feeling reluctant about sharing food which is in conflict with social mores, “Because the groceries are pretty expensive these days and nobody really shares” (Agnes, participant).

Traditional foods were seen as important for ceremonies and for Indigenous identity among some focus group participants. Sociocultural beliefs around the label ‘lazy’ and the changing value of sharing stem from historical factors related to colonialism. Lazy is one of the labels that has been attributed to Indigenous people and appears to have been internalized, thus sustaining racist stereotypes and negative perceptions of Indigenous people (Lutz, 2009). Sharing food is a fundamental cultural value, but food insecurity appears to have had a deleterious effect on this value in communities.

Limitations

The participants in this study were primarily caregivers of students who participated in another component of this study. These caregivers were interested in discussing nutrition, and thus may not represent a broad cross-section within these six First Nation communities. This study was limited by the small numbers of focus group participants relative to the population of each community.

Discussion

Dietary decisions made by caregivers in these First Nation communities are impacted by sociocultural, environmental, and societal/historical level determinants. In the focus groups, participants described how the food systems in their communities have significantly changed during their lifetime. Traditional practices of accessing food from the land has been restricted and has been attributed to
Colonization has resulted in what the Truth and Reconciliation Commission (2015) referred to as cultural genocide:

...the destruction of those structures and practices that allow the group to continue as a group. States that engage in cultural genocide set out to destroy the political and social institutions of the targeted group. Land is seized, and populations are forcibly transferred and their movement is restricted. Languages are banned. Spiritual leaders are persecuted, spiritual practices are forbidden, and objects of spiritual value are confiscated and destroyed. And, most significantly to the issue at hand, families are disrupted to prevent the transmission of cultural values and identity from one generation to the next. (TRC, 2015, p. 1).

This system of devaluing Indigenous cultures has affected food systems in these communities. Participants commented on several factors that have detrimentally affected food systems in their community. These factors include the infringement on, and contamination of, traditional territories; the modernization and marginalization of culture; participation in the mainstream economy; and issues of poverty. Decolonization and the restoration of traditional food systems are offered as a means to revitalizing the food systems in these communities.

**Colonization and Contamination of Traditional Territories**

Access to traditional territories in order to exercise treaty rights to hunt and fish has been hindered by regulations imposed by the colonial government (Chan et al., 2014). Focus group participants noted that some freshwater fish and wild game species have declined. The decline in fish can be attributed to overfishing by commercial and sport fishing, as well as from invasive species (Hudson & Ziegler, 2014). This is compounded by the risk of increased exposure to contaminants associated with consuming freshwater fish and wild game (Davies, 2001). For example, the *Guide to Eating Fish in Ontario* advises limiting the consumption of pickerel and pike due to mercury (Ministry of the Environment and Climate Change, 2015). These contaminants among fish and game populations are a direct result of industrial pollution, which is a colonial activity. As a result, fewer fish and concerns about contaminants have decreased consumption of traditional foods (Willows, 2005). Additional barriers to hunting and fishing practices include time constraints, the absence of a harvester in the household, lack of equipment, and transportation (Chan et al., 2014).

Harvesting naturally occurring food and medicinal plants from the environment has reportedly declined among the focus group participants. This may be due to a number of factors. There has been a loss of plant habitat not only in the traditional territories but within First Nation reserve boundaries as built environments expand. Environmental contamination and climate change have negatively affected plant growth (Power, 2008). Practices such as controlled burning which releases the seeds of different
plant species are not occurring as frequently as in the past (Kimmerer & Lake, 2001). The interdependence of plants and animals is crucial to diverse habitats. A decline in animal species will also bring a decrease in the spread of seeds through animal digestion. Finally, Anishinaabe teachings highlight the importance of maintaining reciprocal relationships with plants, observing that plants must be harvested respectfully in order to flourish (Kimmerer, 2013). This reciprocal relationship must be maintained in order for food and medicinal plants to thrive. These factors may have contributed to the reported decline in the availability of wild berries, as well as other plants used for food.

**Modernization and the Marginalization of Culture**

In the past, procuring food from the land through activities like hunting, fishing, and gardening was not only labour intensive, but key to maintaining social and cultural bonds. The rapid transition to predominantly market food has also been influenced by the decreased availability of smaller game and indigenous fish species. Activities such as harvesting berries and raising livestock have also declined due to changes in socioeconomic conditions, whereby more people are involved in the wage economy, and do not have the time to engage in these activities (Power, 2008). These changes in hunting, fishing, harvesting, and gardening practices have resulted in a decline in the reliance on food from the land.

The decline of gardening activities in these First Nation communities may be due to several reasons. These include smaller, rented properties with a backyard reserved for a field bed; the increase in the commercial production of fruits and vegetables (Dorff, 2014); the loss of gardening knowledge due to the increased availability of commercial produce, decreasing the need to garden; the lack of tools needed for gardening activities; the associated cost of plants and tools; and the labour intensity of gardening (Conway & Brannen, 2014).

The use of the term ‘lazy’ in regards to meal preparation by some participants can be viewed as another way in which the internalized marginalization of Indigenous people is present in some communities or community members. This label likely stems from a stereotype that has been used to describe Indigenous people e.g., ‘lazy Indians’ (Lutz, 2009). This stereotype has been internalized by some participants, and may be a way of avoiding responsibility for well-being. Avoiding or refusing to take responsibility is the result of the colonial legacy of the federal government controlling all aspects of the lives of Indigenous peoples in Canada (Richmond & Ross, 2009). However, using the term ‘lazy’ in a joking manner can be also seen as an act of resistance to this externally imposed label.

**Participation in the Economy and Issues of Poverty**

Dietary decisions are determined by food distribution challenges, namely food insecurity. Socioeconomic status affects food security and participants in this study reported that they rely almost entirely on market foods, and therefore their income directly affects the type and amount of food they can purchase. The quality of store-bought fruits and vegetables is reportedly poor, while processed foods are perceived to be non-perishable and inexpensive. Income also determines whether community
members can afford a vehicle or whether they will require a taxi to transport them to a grocery store. The closest grocery stores are range between five kilometres and 52 kilometres away from these First Nation communities, and thus additional and costly transportation is necessary in order to obtain market fresh food. Some of the communities have established food banks in order to address food insecurity among low income households.

Participants were knowledgeable about healthy foods but consistently making healthy food choices continues to be a challenge due to reasons such as the proliferation of processed foods. Processed foods are readily available, are perceived to be inexpensive, and can be prepared quickly. Processed foods have a longer shelf life because they contain high amounts of preservatives (Moss, 2013). Less perishable foods are selected because people on limited incomes must have food that can an entire month. In addition, cooking skills have diminished along with the perception that there is not enough time to cook from scratch. The practice of preparing traditional foods may have been lost as a result of family interruptions due to residential schools and the Sixties Scoop. Children’s exposure to traditional practices of harvesting food would be significantly impacted by their long-term absence from their family and home community.

**Decolonization and the Restoration of Traditional Food Systems**

The importance of local food systems in addressing food insecurity, nutrition and health in Indigenous communities has been recognized (Kuhnlein, 2009). Indeed, Alfred and Corntassel (2005) suggest that Indigenous peoples ‘decolonize’ their diet with natural food sources as one way to regenerate and transform communities. Participants in this study noted that traditional foods remain crucial to Anishinaabek identity. The communities in this study have initiated activities such as community gardens and community freezers where wild game can be stored and shared within the community. In addition to family hunting practices, these communities also gather together for fall hunting camps. The purpose of these communal hunting camps are to share traditional hunting practices, as well as to assert rights and to maintain stewardship of the land.

The Anishinabek/Ontario Fisheries Resource Centre conducts educational outreach activities in these communities on traditional fish harvesting practices and food preparation. These initiatives are opportunities to revitalize Indigenous food systems by sharing gardening, hunting, and fishing skills by reconnecting to the land and by connecting with other community members. Restoring local food systems moves Indigenous communities towards food sovereignty which can lead to increased access to healthy foods and increased physical activity while reconnecting to the land and supporting the maintenance of cultural identity.

**Conclusion**

Ultimately, colonial policies and legislation have resulted in the loss of traditional territories, infringed on Indigenous hunting and fishing rights, and removed people from their lands that once
provided traditional and nourishing food sources. One of the most significant forces connected to these issues is the legacy of Indian Residential Schools. The Truth and Reconciliation Commission has found that Canada remains systematically, institutionally, and structurally colonial and racist, thus posing ongoing challenges for caregivers that attempt to make healthy dietary decisions in these First Nation communities (TRC, 2012). Some of these challenges are accessing food from the land, having enough money for market foods, and preparing healthy meals from whole foods.

Food systems in these six communities have undergone a rapid transition which have influenced dietary decisions. Participants reported that in the past, food was sourced through traditional activities such as hunting, fishing, gathering, gardening, and raising livestock. At present, however, they reported an almost exclusive reliance on market foods from the grocery store, although traditional foods remain culturally significant, especially for ceremonial feasts. With fewer available small game animals and the scarcity of some indigenous fish species, food insecurity is an issue in these communities. Participants were aware of healthy foods and were concerned about the health effects of a poor diet, but food choices were impacted by the high cost of food, the poor quality of fresh fruits and vegetables, time constraints with less food being prepared from ‘scratch’, and an overall greater reliance on processed foods.

The economic structure in these communities have also changed with more people being involved in the mainstream economy which limits their time to gather and prepare traditional foods. Dietary decisions were found to be influenced by interpersonal, community, and societal level factors. Despite the permeation of colonialism, these First Nation communities are taking steps to revitalize their food systems through activities such as community gardens, fishing, and community hunt camps. These activities are viewed as opportunities to revitalize Indigenous food systems by reconnecting to the land and reinforcing community and kinship bonds. Cultural practices offer a much needed space where more community members can return to traditional foods, activities and values.

References


“It’s a lot of work, and I’m still doing it”: Indigenous perceptions of help after sexual abuse and sexual violence.

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“It’s a lot of work, and I’m still doing it”: Indigenous perceptions of help after sexual abuse and sexual violence.

Abstract
This project used a sequential exploratory design to learn about what Canadian Indigenous people found helpful for dealing with the impacts of sexual abuse and sexual violence, as well as facilitators and barriers to service use. Participants resided in Thunder Bay, Ontario, Canada and identified primarily as Ojibway, Oji-Cree, Cree, and Métis. Talking Circles and individual interviews were integrated with quantitative survey data. The Medicine Wheel was used to organize and describe findings. Spiritual practices included meeting with Elders, attending ceremonies, being outside, teachings, Healing Circles, and using Traditional Healers and Traditional Medicines. Emotional practices included connection, listening and being listened to, validation, cultural connections, self-reflection, belonging, and help with grieving. Physical practices included fasting, having a safe place to go, and sobriety, while mental practices included learning and understanding, non-judgement, learning coping skills, and being persistent. Findings reinforce that supports for sexual abuse/violence must be conceptualized beyond formal supports and be inclusive of the spiritual, emotional, mental, and physical practices used by Indigenous peoples.

Keywords
First Nations; Aboriginal; Indigenous; sexual abuse; sexual violence; services

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Introduction

The health, social, economic, cultural, and political status of Canada’s Indigenous peoples\(^{10}\) must be situated within the legacy of colonization which continues to affect this diverse group of peoples (Kirmayer, 1994; Spitzer, 2005; Waldram, Herring, & Young, 2006; Royal Commission on Aboriginal Peoples [RCAP], 1996). In Canada such colonial policies and processes include the forced removal of children from families and subsequent placement in residential schools and/or foster care, the reserve system and forced relocation of communities, and denial of cultural and linguistic rights (Adelson, 2005; Bombay, Matheson, & Anisman, 2014; Kirmayer, Simpson, & Cargo, 2003; RCAP, 1996; Waldram et al., 2006). This contextualization of historical and collective trauma is particularly relevant to the issue of sexual abuse and violence (Mehrabadi et al., 2008), for which rates are higher for Indigenous peoples compared to the non-Indigenous population (Aboriginal Healing Foundation, 2002; Collin-Vézina, Dion, & Trocmé, 2009; Pearce et al., 2008; Statistics Canada, 2016; LaRocque, 1994; RCAP, 1996, Trocmé et al., 2001). The current incidence of sexual abuse and violence has been linked to widespread abuse in residential schools, and the systematic destruction of Indigenous culture and associated protective factors (see Aboriginal Healing Foundation, 2002; Reeves & Stewart, 2014 for a thorough discussion).

Culture influences one’s approach to coping with life difficulties (Barker-Collo, Read, & Cowie, 2012; Walters, Simoni, & Evans-Campbell, 2002) and also influences help seeking. Authors have been critical of the lack of incorporation of cultural and traditional beliefs with mainstream services (e.g., LaFromboise, Trimble, & Mohatt, 1990; Smye & Mussel, 2001). Indeed, Indigenous peoples are less likely to access mainstream services than non-Indigenous peoples, and tend to terminate earlier (Garrett & Herring, 2001; LaFromboise et al., 1990). While there are many reasons for these differences in help-seeking, services’ lack of cultural adaptation to conceptualizations of healing and supports is a contributing factor (Garrett & Herring, 2001; Wihak & Price, 2006). There is a need to acknowledge and value what Indigenous people find helpful in dealing with the impacts of sexual abuse and violence. It is important to listen to Indigenous perspectives and experiences, and share the knowledge gained to the benefit of efforts to support healing.

In 2013, following identification of information needs and knowledge gaps regarding services for sexual abuse/violence in the community, the Naadmaagewin Aboriginal Domestic Violence Committee (NADVC) initiated a research project. The goal of this project was to listen to and understand the experiences of participants and learn about what Indigenous people in Thunder Bay (Ontario, Canada) and area\(^{11}\) found helpful for dealing with the impacts of sexual abuse/violence. Information specific to

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\(^{10}\) The First Peoples of North America, including First Nations, Métis, and Inuit peoples in Canada (Reeves & Stewart, 2014).

\(^{11}\) We wish to acknowledge the wide diversity among participants in this research who self-identified as Ojibway, Oji-Cree, Cree, and Métis and included people living in Thunder Bay as well in First Nation communities/reserves.
service providers and organizations was also sought (e.g., appropriateness and quality of services). The focus of the current article is on perceptions of support for sexual abuse/violence: What did Indigenous peoples find helpful? In answering this question we looked at perceptions of formal supports as well as cultural and traditional practices.

**Relationship**

The project was undertaken by a Research Group consisting of both Indigenous and non-Indigenous peoples (NADVC members and a university-based researcher). The NADVC reviewed and approved this project prior to its implementation, and organizations from which participants were recruited provided approval prior to implementation. The NADVC maintains control and ownership of this project including data and final reporting of findings and provides participants with access to their data if so desired. The university Research Ethics Board reviewed and approved this project. An Indigenous Advisory Committee consisting of two Elders and two Indigenous Scholars advised on matters such as cultural sensitivity and respect, Indigenous ways of knowing, research methodology, and collection and interpretation of data. Knowledge resulting from the larger project was shared with participants and the community in several ways. We engaged in member checking with participants from Talking Circles and interviews, where emerging findings were contextualized and mutually explored. Two presentations (one for the general community, and one for service providers) were conducted, and a snapshot booklet (brief summary of general findings) was created and distributed in the community. The present article is the final step in our knowledge sharing plan – integration of the qualitative and quantitative findings, and dissemination to a larger group of knowledge-users.

**Methods**

In October 2013 the research team began drafting the methods to meet project goals, initially consisting of a survey to be distributed at service agencies in the community. Based on feedback from the Advisory Committee that a qualitative approach would be the most appropriate starting point, these methods were expanded to a sequential exploratory design whereby qualitative data were collected first followed by collection and analysis of quantitative data (Creswell & Plano Clark, 2018). Talking Circles and interviews were conducted first, and the information shared was used to inform a survey. The overall focus of both methods was to listen to what Indigenous people in Thunder Bay and area found helpful in dealing with the impacts of sexual abuse and violence.

**Talking Circles and Interviews**

In Spring 2015 Indigenous adults were invited to participate in interviews and Talking Circles through posters placed in service agencies and public places in the community; flyers were also distributed to clients by reception at participating organizations. Participants received gift cards to thank them for their participation.
Questions to facilitate the Talking Circle explored supports and barriers to getting help following sexual abuse/violence, what service organizations are (and are not) doing well, and what was found helpful in dealing with the impacts of sexual abuse/violence. The Talking Circles were conducted by local Indigenous Elders and Indigenous facilitators (female Elder and facilitator for the women’s Talking Circles, and male Elder and facilitator for the men’s Talking Circles). The Elders and facilitators had knowledge of and experience with sexual abuse/violence clinical work and group dynamics. All are respected in the community for their leadership and knowledge and practice of tradition and culture. Facilitators posed the Talking Circle questions, ensured the group rules and boundaries were respected, and facilitated the group dynamic. The Elder was available to provide aid should participants be in immediate and urgent need of assistance. Facilitators were also able to provide information and referrals for various services as needed. An Indigenous research assistant recorded the information shared during the Talking Circle through notes and use of visual aids (e.g., flip chart).

Six Talking Circles were held (three for men and three for women; participants self-identified as male or female). The Talking Circles proceeded as follows: (1) Individual welcoming by Facilitators, discussion of the purpose of the research, and obtaining of consent; (2) Opening Ceremony with Smudging; (3) Discussion of an Ethical Space, and participant identification of how an Ethical Space can be created; (4) Posing of questions/topics. A sacred eagle feather\textsuperscript{12} was passed around in a clockwise direction. Each participant could choose to speak when the feather was passed to them, or they could choose not to speak and pass it to the next person. In responding to each question/topic, there were as many rounds as the participants wished; (5) Group discussion of emerging themes/key points (member checking); (6) Closing ceremony; (7) Refreshments.

In addition to the Talking Circles, seven individual interviews were also conducted. The interviews were conducted by a local Indigenous clinician who has experience working with clients that have experienced sexual violence/abuse. All interviews were conducted in a private space and audio-recorded. The interviewer also asked if the participant would like a follow-up phone call within one week to provide additional assistance or resources. The interviewer could provide help if the participant was in immediate and urgent need of assistance (e.g., experienced a strong emotional response; triggering). All interview participants received a list of programs and resources in the community, should they wish to utilize a resource.

The Talking Circles and interviews were audio-recorded with the participants’ written consent, and later transcribed (anonymizing occurred at the level of transcription). The information shared by participants was used to develop themes organized within the four quadrants of the Medicine Wheel:

\textsuperscript{12} Various objects are used by First Nations peoples to facilitate Talking Circles. The holder of the (sacred) object has the right to speak, and all others have the responsibility to listen and not interrupt (Nishnawbe Aski Nation, 2002). The eagle feather is symbolic for taking away one’s pain and suffering. It helps provide the courage and strength to voice things one might not otherwise. A sacred eagle feather was used for these purposes in our Talking Circles.
Spiritual, Emotional, Mental, and Physical. It is acknowledged that these quadrants are interdependent.

Two additional Circles were held where participants assisted in connecting themes to the Medicine Wheel in a manner that best represented their experiences (member-checking).

Survey

In Spring 2016 we administered a survey based on analysis of the information shared in the Talking Circles and interviews. The goal was to learn about what a larger group of Indigenous people found helpful in dealing with the impacts of sexual abuse/violence, and to ask specific questions about service agency barriers and supports (not reported here). A convenience sample of Indigenous adults were invited to complete the survey through posters placed in service agencies and public places in the community. We also set up tables at service agencies and at a local business/shopping centre to recruit participants. Participants received gift cards to thank them for their participation. The survey included questions about participants’ demographic information (e.g., age, sex, education) and experiences in getting help after experiencing sexual abuse or sexual violence; we asked survey participants to rate the perceived helpfulness of a variety of supports for sexual abuse/violence. Participants completed these ratings using a Likert scale that ranged from 1 (“very unhelpful”) to 5 (“very helpful”). The survey took approximately 15 minutes to complete and was available in paper format and electronic format.

Results

Twenty-two Indigenous people participated in the Talking Circles and interviews, and 103 Indigenous people completed the survey. Among survey participants, most described themselves as Ojibway (58%) and Oji-Cree (15%); we also had representation of Métis (7%) and Cree (3%) peoples. Participants’ average age was 38 years old (SD = 12.2; range = 14 – 65 years). Participants were most commonly female (64%), single (45%), married/common-law (36%) or separated/divorced (7%). Fifty-eight percent of the survey sample had a high school education or less. Many survey participants (68%) were unemployed and had an income under $25,000 per year. While 90% of participants lived in the city, 72% had previously lived on a First Nation community/reserve. Thirteen percent had attended a residential school, while 57% had at least one family member who attended a residential school.

Mental Health, Substance Use, and Other Difficulties

Overall, 70% of survey participants reported at least one experience of sexual abuse or sexual violence. However, 38% of people who experienced sexual abuse/violence did not seek support for it. Amongst people who reported sexual abuse/violence a large majority also reported other experiences of abuse (emotional, physical), relationship difficulties, depression, and anxiety (Table 1). As can be seen in Table 1, not everyone who experienced difficulty tried to get support for it. Of significance for this study’s topic, the largest difference was observed for sexual abuse/violence. Following this, the next biggest gaps were for suicidal thoughts (29.6% of people did not seek support for this), emotional abuse (28.1%), and physical abuse (26.7%). The smallest gaps were for suicide attempts (7.1%), drug use (14.1%), anxiety (15.5%), and alcohol use (16.9%). There were no differences in sex for help-seeking.
Perceptions of Help After Sexual Abuse/Violence

A central focus of this project was to determine what Indigenous people found helpful in dealing with the impacts of sexual abuse/violence. Figure 1 shows themes derived from Talking Circles and individual interviews organized within the four quadrants of the Medicine Wheel: Spiritual, Emotional, Physical, and Mental. These themes were validated in our survey sample. The following sections integrate the qualitative and quantitative data and are organized by Medicine Wheel quadrant.

Spiritual Practices

Participants described the helpfulness of numerous spiritual practices (Figure 1) including ceremonies, meeting with Elders, and being in nature. A Talking Circle participant described how she became open to healing:

So I started talking to Elders, I started going to treatment centres and this is where I found I could relate and start talking. Sweat lodges, the Elders ... I could still cry. I cry easy now. Before I couldn’t. I got so much. So much. But that’s part of it. Letting go. My tears and what I talk about. (Participant).

This same participant later explained:

Sweat lodges keep me grounded. Because I can go in there and cry and pray. And even in circle now. I couldn’t before, you know. I thought, ‘I’m not going to cry here.’ I’m getting in touch with my, you know ... my hurts. (Participant).

These practices were also valued by survey participants, including meeting with Elders ($\bar{X} = 3.9$, $SD = .97$), attending cleansing ceremonies such as Sweat Lodge and Cedar Lodge ($\bar{X} = 4.0$, $SD = 1.1$), Sharing Circles ($\bar{X} = 3.9$, $SD = 1.1$), and Healing Circles ($\bar{X} = 3.9$, $SD = 1.0$).

The use of Traditional Medicines ($\bar{X} = 3.9$, $SD = 1.0$), Sacred Items (e.g., smudging, feather, drumming; $\bar{X} = 4.1$, $SD = .96$), and Traditional Healers ($\bar{X} = 4.0$, $SD = .90$) were also rated as helpful by survey participants. As explained by a Talking Circle participant, “…For me, the way of life of, you know, of smudging, sweat lodges, circles, has been helping me a lot on my journey.” Another participant stated:

I don’t think about reaching for the bottle to medicate myself. If something is bothering me, maybe I’ll smudge. Or ask the creator for help. Or use the service line, the toll-free number that, you know, that could help me. Find someone that I’m comfortable to talk to. (Participant).
Table 1.  
Mental health, substance use, and other difficulties amongst survey participants who experienced sexual abuse/violence \((N = 71)\).

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Experienced</th>
<th>Tried to get support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty with alcohol</td>
<td>54 (76.1%)</td>
<td>44 (62.0%)</td>
</tr>
<tr>
<td>Difficulty with drugs</td>
<td>52 (73.2%)</td>
<td>40 (56.3%)</td>
</tr>
<tr>
<td>Depression</td>
<td>59 (83.1%)</td>
<td>45 (63.4%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>57 (80.3%)</td>
<td>46 (64.8%)</td>
</tr>
<tr>
<td>Emotional abuse</td>
<td>64 (90.1%)</td>
<td>44 (62.0%)</td>
</tr>
<tr>
<td>Physical abuse or violence</td>
<td>62 (87.3%)</td>
<td>43 (60.6%)</td>
</tr>
<tr>
<td>Sexual abuse or violence</td>
<td>71 (100%)</td>
<td>44 (62.0%)</td>
</tr>
<tr>
<td>Disordered eating (under or overeating to cope)</td>
<td>37 (52.1%)</td>
<td>23 (32.4%)</td>
</tr>
<tr>
<td>Difficulty attending work</td>
<td>40 (56.3%)</td>
<td>24 (33.8%)</td>
</tr>
<tr>
<td>Difficulty attending school</td>
<td>45 (63.4%)</td>
<td>30 (42.3%)</td>
</tr>
<tr>
<td>Relationship difficulties</td>
<td>60 (84.5%)</td>
<td>42 (59.2%)</td>
</tr>
<tr>
<td>Self-harm</td>
<td>37 (52.1%)</td>
<td>25 (35.2%)</td>
</tr>
<tr>
<td>Suicidal thoughts</td>
<td>48 (67.6%)</td>
<td>27 (38.0%)</td>
</tr>
<tr>
<td>Suicide attempt</td>
<td>32 (45.1%)</td>
<td>27 (38.0%)</td>
</tr>
<tr>
<td>Hospitalized for mental health reasons</td>
<td>20 (28.2%)</td>
<td>---</td>
</tr>
</tbody>
</table>
Figure 1.

Supports after sexual abuse/violence, organized within the quadrants of the Medicine Wheel.

Survey participants also found spending time in the bush, outdoors, or near water helpful ($\bar{X} = 4.2, \ SD = .95$). One Talking Circle participant described her experience:

There’s that ancient teaching: when we share our voice, we share our spirit, we share the journey. We shared it with the trees, the animals, the bugs, the bees, the flowers, the weeds, the river, the lake, with anything that was within hearing distance. And you’d be so exhausted when you’d come back, you couldn’t react to anything but just be [totally] quiet. It was... you’d stop, and it would be the total silence of the... the tree leaves, you hear the tree leaves, you begin to hear the birds, actually some of the animals. (Participant).
Another participant said:

When I was in [town] a lot of my healing was done by the water, by myself. And I couldn’t understand it, it was just the only time I felt peace, or if I was feeling anxiety ... I would go out to the lake and just sit and listen to the water.... that was my way of finding my peace. (Participant).

**Emotional Practices**

Emotional practices were also valued by participants (Figure 1). The concept of connection with others, and with culture (e.g., “And going to powwows, gatherings ... That’s resources I know that’s been helping me through.”) was particularly strong.

I help people remember their family and friends. And the supports we give each other all the time. ... But unless we reach out and kind of connect with each other, it’s pretty easy to feel like you’re out there all by yourself on a limb dangling ... (Participant).

Another participant described her need for connection in this way:

The barrier was my own self, my own shame. My own fear of needing people. I haven’t discovered that until this year... was it this year? Yeah, this year, after taking another anger group. You know, that connection is actually a need. And I’d been saying to myself, “Oh, I don’t need people.” That's how I've been surviving, eh. So for me that was a barrier, because I didn’t want to admit that I had all these yucky, yucky deep feelings and needs. But I went there, and lucky for me there was a few familiar faces there, there were elders there, Aboriginal people working in programs for me, and every time we’d get a hug and it was nice. (Participant).

This theme was also evident in our survey data; participants found connection with others to be helpful in dealing with the impacts of sexual abuse and violence, be it through talking with a trusted family member or friend ($\bar{X} = 4.1, SD = 1.0$), listening to stories of others ($\bar{X} = 4.0, SD = 1.0$), or meeting with an Elder as previously noted. Although both males and females found peer support to be helpful, here there was a difference in sex in regards to males finding peer support more helpful than females ($t_{43} = 1.8, p = .03$).

Helpful connections with professionals (e.g., counsellors) were also described by participants:

Well, what worked, with that first counsellor there, was just that total... she was really, for me, I think, all the time, I think I was angry at her once that I was aware...
of and she was so kind and so gentle. And she was the first worker that worked with me for my sexual abuse. (Participant).

It took me a while to open up. It wasn’t like one or two sessions, it’s a while for me to start having, you know, grieving my loss. And all the shame that was stuck there started coming out and I had encouragement or that, you know, it’s okay to cry. And I had to believe that because I wanted to get well. (Participant).

A third participant stated: “And still seeing my counsellor. And I am really so, so, so, grateful for her, she was what I needed.” Survey participants also found these professional connections helpful, including individual counselling ($\bar{X} = 4.1, SD = .86$), group counselling ($\bar{X} = 3.7, SD = 1.0$), and crisis services ($\bar{X} =3.6, SD = 1.2$). Males found group counselling more helpful than did females ($t[45] = 2.6, p = .01$).

**Physical Practices**

Helpful physical practices included sobriety, going for a sweat, and fasting (Figure 1). As one participant stated, “I went fasting with an Elder, and it was a really beautiful experience …” Another participant shared how she finds driving helpful:

> I drive a lot, too. I drive a lot by myself. Because that’s when I cry, when I’m by myself. When my kids are not around. I play my music loud and I just give ‘er. I just cry. …. But I enjoy being out on the highway where the trees and I just think, like, it’s beautiful, and I just... even when I look at that picture it reminds me of [home community]. Being at that... in front of that lake and the river, [home community]. Just listening to the water, it’s so soothing, like, just... oh man, it’s just do healing, so powerful. Because you can just sit there and reflect. No one’s around, it’s just the animals there, the earth, the wind. Oh, I just love that. (Participant).

Sobriety was often discussed as an important step towards healing, for example, “After 12 months of being sober and going to treatment 12 months later, I had a better chance at recovery … And I had more understanding of where I was coming from.” Survey participants agreed that these physical practices were helpful, including fasting/vision quest ($\bar{X} = 3.6, SD = 1.1$) and physical activity (e.g., exercise; $\bar{X} = 4.2, SD = .95$).

**Mental Practices**

Learning, understanding (e.g., effects of violence; survival skills; counselling; insight), and being persistent were among the helpful mental practices described (Figure 1). As previously described, survey participants found individual and group counselling helpful. Reading ($\bar{X} = 4.0, SD = .88$), internet resources ($\bar{X} = 3.8, SD = .96$), and self-help (e.g., books; $\bar{X} = 3.8, SD = .89$) were valued by survey participants. Various types of learning were described, such as “I am getting back to my Native culture.
I am learning again… I listen to Elders… I listen to documentaries.” Learning a traditional language was also described: “I’m trying to learn how to write in my own language.” Another participant found formal education to be helpful: “And if anything, go back to school. Get your grade 12. You just need your education. Doors open for you. I’ve always advocated that. Go and get your grade 12.” Another participant described her experience as a learning process:

It’s like every lesson is a learning experience, that’s how I… everything that went… happened in my past is all lessons and they’re… even though they were tough and painful it’s all learning, learning. I learned I’m now… I don’t hate them. I turned them around and make them a learning experience and, you know, share them anybody that’s struggling maybe in the sharing group and tell them my story, where I came from and what I went through and where I am now. That’s what… maybe somebody will be, you know, don’t stay in the dark, there’s always a light at the end of the tunnel, like you know, I was in dark space a lot of times. And when I look back I just came out of a dark space and now I’m in a space where there’s… a better space. (Participant).

Determination in seeking supports, finding a professional to connect with, and overall steadfastness with one’s healing journey, were examples of the perseverance participants described. One participant described her persistence in this way:

I want to start doing counselling again. … It’s always like that for me. I’m going to work on myself. Like I see some people that went before me, I hear their stories and they go to meetings somewhere and oh, she’s doing wonderful, and I want to be like that too. But how do you get there? For me, where I was to be, to go there, to be in that space? And I didn’t know it was going to be a long journey, a lot of things, of garbage to get rid of, a lot of things that happened in my past, and I had to do a lot of, you know, purging out of those things that I shoved down there. It’s a lot of work and I’m still doing it … I’ve come a long ways. (Participant).

Discussion

The overall goal of this project was to listen to and understand the experiences of participants and learn about what Indigenous people in Thunder Bay and area found helpful for dealing with the impacts of sexual abuse. Given the influence of culture on coping and help-seeking it is not surprising that participants described concepts that are inherent within Indigenous worldviews (Graham & Martin, 2016): Indigenous peoples used numerous practices to promote healing and wellness. Spiritual practices included meeting with Elders, attending ceremonies, being outside, teachings, Healing Circles, and using Traditional Healers and Traditional Medicines. Emotional practices included connection (e.g., with family, friends, counsellor/physician), listening and being listened to, validation, cultural connections,
self-reflection, belonging, and help with grieving. Physical practices included fasting, having a safe place to go, and sobriety, while mental practices included learning and understanding, non-judgement, learning coping skills, and being persistent. Connection and belonging were powerful themes throughout our findings, whether the connection be spiritual, emotional, with self, friends, family, care providers, or connection with the land and water.

These findings parallel the literature calling for alternatives to mainstream approaches for Indigenous peoples (Duran, 2006; Gone, 2011; Reeves & Stewart, 2014), culture as treatment (Gone, 2013) and more specifically how the medicine wheel quadrants and related concepts are important for healing. For example, relationships, spiritual beliefs and cultural practices positively impacted néhiyawak (Plains Cree) mental health and well-being and were described as necessary for optimal mental health and well-being (Graham & Martin, 2016); Similarly, strong connections to the land and traditions, spirituality, and community connection were strengths related to mental health perceptions and practices in a northern Cree community (Danto & Walsh 2017). Urban-based First Nations peoples described the importance of gaining balance in the four realms of spiritual, emotional, mental, and physical health for addressing health issues (Hunter, Logan, Goulet, & Barton, 2006) and a literature review that included Indigenous communities from around the world integrated the findings into a framework for well-being based on medicine wheel teachings (Rountree & Smith, 2016). The information shared by participants about supports for sexual abuse and violence are consistent with this larger body of work: numerous spiritual, emotional, mental, and physical practices were helpful for healing from sexual abuse/violence. Our findings also reinforce that supports for sexual abuse/violence must be conceptualized beyond formal supports (e.g., counselling) and be inclusive of the spiritual, emotional, mental, and physical practices used by Indigenous peoples. Unfortunately, these practices are typically absent from mainstream services and thus contribute to unmet needs for Indigenous clients (Reeves & Stewart, 2008; Simonds et al., 2011).

Although the focus was on sexual abuse/violence, a large majority of our survey participants reported additional difficulties with abuse/violence, mental health, substance use, and relationship difficulties. These findings were not surprising given the epidemiological research (which has consistently demonstrated high rates of mental health, addiction, and family violence; First Nations Centre, 2005; First Nations Information Governance Centre, 2012) and the larger literature on mental health outcomes for people who experience sexual abuse/violence. Our survey data also indicated that not everyone who experienced a specific difficulty sought support for it, the largest difference (between experience and seeking support) being for sexual abuse/violence. In our survey sample people were least likely to seek support specifically for sexual abuse/violence, and most likely to seek support for drug use, anxiety, and alcohol use. However, we must keep in mind that this partitioning of experiences and supports is artificial: people connect to a service or support for one or more specific reasons, and also carry with them other experiences and needs. Also salient is the person’s conceptualization of health, which in the Anishnawbe tradition includes emotional, physical, spiritual, and mental aspects of the self.
Thus, the segmenting of mainstream mental health services (and more broadly, health services) is particularly problematic for Indigenous people who have experienced sexual abuse/violence. Unfortunately, mainstream health services tend to be compartmentalized (Wyrostok & Paulson, 2000) and in contrast to a holistic conceptualization and treatment of illness from an Indigenous perspective. Our findings support the importance of the cultural contextualization of services and trauma-informed care (Reeves & Stewart, 2008).

Persistence was also a theme, both with trying different practices and with one’s overall journey. Other research has examined the significant resiliency of Indigenous peoples (e.g., Aboriginal Healing Foundation, 2003; Isaak et al., 2015; Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011) and in line with this research, participants in our study sought supports for sexual abuse/violence often within the context of dysfunctional environments. The metaphor of a “healing journey” was salient for participants and is in keeping with similar descriptions in previous research with Canadian Indigenous peoples (e.g., Waldram, 2013). These findings compliment a conceptualization of resilience that incorporates multifactorial pathways to healing (Isaak et al., 2015).

Limitations

Our data were based on a convenience sample of Indigenous peoples recruited from one Canadian city; findings may not be generalizable beyond the local context. Participants identified as Ojibway, Oji-Cree, Cree, and Métis, yet our analyses were based on the overall group. Recognizing the wide diversity amongst these cultures (as well as amongst other Indigenous peoples) our findings may not have captured meaningful group differences and may or may not apply to all Indigenous cultural groups.

Conclusion

Canada’s Indigenous peoples continue to be affected by a legacy of colonialism and marginalization, affecting health and wellbeing and with specific impacts on sexual abuse and violence. Despite the resilience and persistence displayed by participants in this study, the sexual abuse and violence experienced by Canadian Indigenous peoples remains unacceptably high and there is an urgent need to both stop the abuse and address its impacts. This research contributes to the current body of knowledge regarding the numerous pathways to healing utilized by Indigenous peoples who experienced sexual abuse and violence. It is important to acknowledge and value what Indigenous people find helpful in dealing with the impacts of sexual abuse and violence, and for this insight to be used when planning relevant services for Indigenous peoples. Beyond cultural awareness, service providers working with Indigenous clients must practice from a place of cultural safety and cultural competence (National Aboriginal Health Organization, 2008) as well as provide trauma-based care that is informed by the broader context of colonialism and marginalization (Reeves & Stewart, 2014). Persistence and resiliency along the healing journey are also important: As one participant voiced, “It’s a lot of work, and I’m still doing it”. It is our hope that this project highlights the numerous pathways to healing utilized by
Indigenous peoples. Supports for sexual abuse/violence must be conceptualized beyond formal services and be inclusive of the spiritual, emotional, mental, and physical practices used by Indigenous peoples.

References


Effectiveness of an Outreach Model of Care for Rheumatology Specialty Clinics to an On-Reserve First Nations Community.

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Effectiveness of an Outreach Model of Care for Rheumatology Specialty Clinics to an On-Reserve First Nations Community.

Abstract
A model of care consisting of rheumatology specialty services embedded in the primary care system on a First Nations reserve was instituted to reduce barriers to care and improve inflammatory arthritis outcomes for patients. We assessed the effectiveness of this model of care on disease activity measures and patient-reported outcomes over 7 years. Patients were enrolled in a longitudinal cohort at the Siksika Nation in Alberta. Clinical characteristics, treatment recommendations and disease activity measures were systematically recorded over follow-up. Mixed-model regression was performed to determine rates of change for continuous measures. 59 participants (78% female; M = 47 years, SD = 13), predominantly with rheumatoid arthritis (RA; n = 36), were followed for an average of 29 months (SD = 23). Swollen and tender joint counts decreased significantly (change per month: -0.20, 95% CI -0.29 to -0.10, and -0.20, 95%CI -0.34 to -0.06, respectively) but pain, physician global and function scores did not significantly improve (all p > 0.05). Patient global evaluation scores worsened over time (change per month 0.08, 95% CI 0.029 to 0.131, p = 0.002). Inflammatory markers improved at a slower rate in patients with incident compared to incident disease. Disease-modifying agents were escalated for moderate or high disease activity at 64% of RA visits, with justifications for not escalating or application of local treatment approaches in all but one instance. Despite improvement in swollen and tender joint counts and adherence to current treatment paradigms, patient-reported outcomes did not significantly improve during follow-up. Further innovation is required to meet relevant outcomes.

Keywords
Inflammatory arthritis, First Nations, Outcomes

Introduction
First Nations Canadians experience high prevalence rates of inflammatory arthritis (IA) that include rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), and spondyloarthritis (SpA), and with more severe consequences compared to non-First Nations populations. RA affects two to three times as many First Nations people in Manitoba (Barnabe, Elias, Bartlett, Roos, & Peschken, 2008) and Alberta (Barnabe et al., 2017), respectively, compared to non-Indigenous populations. SpA also occurs at 1.5 to 3 times the rate of non-Indigenous populations (Barnabe et al., 2017). Increased disease severity has been reflected through higher disease activity scores and a predilection to involvement of large joints, resulting in worse physical function compared to Caucasians (Peschken et al., 2010). Utilization of rheumatology specialty care is reduced among First Nations populations (Barnabe et al., 2017), potentially explained by geographic and economic barriers to health services, but also related to poor care experiences in the health system, and competing priorities of other health conditions and roles and responsibilities to family and community (Thurston et al., 2014). Along with cultural competency
education for healthcare providers, the development and implementation of innovative models of care were proposed as solutions to improve arthritis care outcomes (Thurston et al., 2014).

The Arthritis Alliance of Canada, in collaboration with the Canadian Rheumatology Association’s Optimal Care Committee, has championed the development and evaluation of models of care for IA to ensure high quality and evidence informed care is provided to Canadians (Ahluwalia, Frank, Mosher, & Zummer, 2014; Barber et al., 2016). Here, we describe patient outcomes of a model of care for arthritis patients instituted at the Siksika Nation in Treaty 7 Territory, a First Nations reserve in southern Alberta with 6,000 residents and with a primary health clinic located 100 kilometers from the nearest tertiary care centre in Calgary, Alberta.

Methods

Model of Care

The Siksika Health & Wellness Clinic is an established primary health centre providing a range of services, including family physician and nurse practitioner visits, laboratory and diagnostic imaging, and is co-located with dentistry, optometry, community health, mental health, pharmacy and home care services. A tripartite agreement exists between the First Nations and Inuit Health Branch, Alberta Region, and Siksika Nation to ensure autonomous delivery of health services. The Siksika Nation was the first community in Alberta to institute an alternative payment plan (salary-based model) for family physicians, and has successfully established outreach services in nephrology (Ward et al., 2013), pediatrics, and dermatology. Rheumatology specialty services were added in 2010, accepting patients through both self-referral (advertised through a variety of community recruitment strategies such as advertisements through local media, recruitment at the local health fair or a community research assistant) and provider referral (i.e., family physician or nurse practitioner) mechanisms at weekly clinics held over 14 months in 2011-2012. This schedule was thereafter modified to a monthly clinic. In the interval between scheduled rheumatologist clinics, patients with inflammatory arthritis conditions are assessed by the primary healthcare providers in the community, who would directly consult with the rheumatologist as needed. Support from local nurses providing clinical care through a home care program was provided by the Nation.

Participants

From all patients assessed in the model of care during the time frame of the study ($n = 271$), consenting patients with IA conditions were enrolled into a longitudinal cohort to capture clinical diagnosis and disease characteristics, treatment recommendations and disease activity measures. We included participants enrolled between June 2011 and March 2016, with follow-up data available to March 2017.
Measures

At the initial visit, clinical diagnosis, demographics (age, sex), comorbid medical conditions, smoking status, family history of rheumatic disease, serology (anti-nuclear antibodies, ANA, at a serum dilution of 1/160), rheumatoid factor (RF), anti-cyclic citrullinated peptide antibodies (ACPA), disease characteristics for all patients with IA, and treatment history for patients with prevalent IA were recorded. Disease activity measures (Tender Joint Count (TJC), Swollen Joint Count (SJC), Physician Global Score (MD Global), erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), and patient-reported outcomes (Patient Global Evaluation Score, Pt Global), Health Assessment Questionnaire (HAQ), Fatigue Visual Analog Scale (VAS) Pain VAS, and Sleep VAS were systematically recorded at baseline and over the course of follow-up. Additionally, the DAS28 score based on 28 joint counts and using the ESR (or CRP) were calculated for patients diagnosed with RA. For treatment strategy, each individual at each visit was classified as: having received a steroid injection (either intramuscular for bridging, or intra-articular/intra-bursal for disease management); recommended to maintain current treatment (i.e. no treatment changes required); taper therapy; initiate a new non-biologic disease-modifying anti-rheumatic drug (DMARD); initiate a new biologic DMARD; or continue/use an oral steroid.

Outcomes

Change in disease-activity measures (TJC, SJC, CRP, ESR, MD Global) and patient-reported outcomes (HAQ, Fatigue VAS, Pain VAS, Sleep VAS, Pt Global) was evaluated for all patients. Changes in disease-activity measures that were specific to RA (DAS28 ESR/CRP) were additionally evaluated, as was a comparison between incident and prevalent cases. We determined if therapy was escalated for RA participants in moderate and high disease activity states (DAS28 ESR >3.2, Fransen & van Riel, 2006; or DAS28CRP >2.9, Kuriya et al., 2017) if DAS28ESR not available according to a treat to target strategy, with escalation defined as either the addition of a new non-biologic or biologic DMARD, and also including the use of steroid (oral and parenteral) in the definition.

Statistical Analysis

Baseline disease activity, patient-reported outcomes, disease duration (for prevalent cases), demographics, and prognostic factors for participants were descriptively summarized. Changes in disease activity measures and patient-reported outcomes were estimated with multilevel mixed-effects linear regression models, adjusting for baseline HAQ score, age, gender, smoking status, as well as baseline SJC28 and TJC28. Comparisons in baseline characteristics between prevalent and incident cases and longitudinal changes in disease activity for both groups were done using t-tests and chi-square tests. All analyses were performed using STATA (version 14).

Relationship

Ethics. In collaboration with Siksika Health & Wellness and the Siksika Nation, a memorandum of understanding and a research agreement for all parties involved was drafted and implemented. This
study was conducted with heed to the Ownership, Control, Access and Possession (OCAP®) principles for research with First Nations communities. OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC)((FNIGC), 2011). Individual consent was obtained following ethics approval obtained through the Conjoint Health Research Ethics Board at the University of Calgary.

Results

Cohort

In total, 59 patients with IA conditions, from 76 IA patients assessed by the rheumatologist, provided consent to participate in the longitudinal study. They were 78% female, with a mean age of 47 years ($SD = 13$) (Table 1). Clinical diagnoses included 36 with RA; 8 with SLE and related connective tissue diseases; 7 with Psoriatic arthritis (PsA); 3 with Juvenile Idiopathic Arthritis (JIA); 2 with SpA, 2 with crystal arthritis; and 1 person with undetermined IA. Thirty-one patients (53%) had incident, and 28 (47%) had prevalent disease. The mean disease duration in prevalent cases was 16 ($SD = 13$) years. At baseline, 63% of participants had at least one comorbidity, with the mean number of comorbidities for this group being 2.2 ($SD = 1.1$). Smoking was frequent with 79% of participants being current or past smokers.

Table 1.

Characteristics of Participants at Study Inception. Results are reported as mean (SD) or % as appropriate, unless indicated.

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<th></th>
<th>Total IA cohort ($n = 59$)</th>
<th>Prevalent Cases ($n = 28$)</th>
<th>Incident Cases ($n = 31$)</th>
</tr>
</thead>
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<tr>
<td>Age</td>
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<td>47.2 (13.4)</td>
<td>47.2 (12.1)</td>
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<tr>
<td>Female</td>
<td>78%</td>
<td>86%</td>
<td>71%</td>
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<td>Smoker (Current or past)</td>
<td>78%</td>
<td>76%</td>
<td>81%</td>
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<td>Proportion with comorbidity *</td>
<td>63%</td>
<td>54%</td>
<td>71%</td>
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<td>Number of comorbidities **</td>
<td>2.2 (1.1)</td>
<td>2.2 (1.1)</td>
<td>2.3 (1.1)</td>
</tr>
<tr>
<td>Tender Joint Count (/28)</td>
<td>8.7 (7.7)</td>
<td>6.4 (6.8)</td>
<td>10.8 (7.9)</td>
</tr>
<tr>
<td>Tender Joint Count (/68)</td>
<td>15.6 (11.3)</td>
<td>11.3 (10.3)</td>
<td>19.3 (10.9)</td>
</tr>
<tr>
<td>Swollen Joint Count (/28)</td>
<td>5.5 (5.7)</td>
<td>4.9 (6.1)</td>
<td>5.9 (5.5)</td>
</tr>
<tr>
<td>Swollen Joint Count (/66)</td>
<td>9.7 (8.5)</td>
<td>8.0 (8.9)</td>
<td>11.1 (8.0)</td>
</tr>
<tr>
<td>DAS28 ESR (if RA)</td>
<td>4.4 (1.3)</td>
<td>4.2 (1.5)</td>
<td>4.5 (1.0)</td>
</tr>
<tr>
<td>DAS28 CRP (if RA)</td>
<td>4.5 (1.6)</td>
<td>4.4 (1.7)</td>
<td>4.5 (1.5)</td>
</tr>
<tr>
<td>Health Assessment Questionnaire Score</td>
<td>1.35 (0.71)</td>
<td>1.51 (0.65)</td>
<td>1.22 (0.74)</td>
</tr>
<tr>
<td>Pain (0-10 Visual Analog Scale)</td>
<td>6.2 (2.5)</td>
<td>5.9 (2.6)</td>
<td>6.4 (2.5)</td>
</tr>
<tr>
<td>Patient Global Evaluation Score (0-10 Visual Analog Scale)</td>
<td>5.0 (2.6)</td>
<td>4.8 (2.7)</td>
<td>5.1 (2.5)</td>
</tr>
<tr>
<td>Physician Global Evaluation Score (0-10 Visual Analog Scale)</td>
<td>3.5 (2.8)</td>
<td>2.9 (3.1)</td>
<td>4.4 (2.1)</td>
</tr>
<tr>
<td>Erythrocyte Sedimentation Rate (mm/hr)</td>
<td>21.2 (22.1)</td>
<td>21.5 (23.4)</td>
<td>21.0 (21.5)</td>
</tr>
<tr>
<td>C-Reactive Protein (mg/dL)</td>
<td>0.8 (1.4)</td>
<td>0.7 (1.0)</td>
<td>0.8 (1.7)</td>
</tr>
</tbody>
</table>

Note: Results are reported as mean (SD) or % as appropriate, unless indicated.

* Comorbidities recorded include ischemic heart disease, transient ischemic attack, hypertension, hepatitis, kidney disease, diabetes, osteoarthritis, and cancer

** Calculated if at least one comorbidity reported

Legend: IA Inflammatory Arthritis; DAS28 ESR Disease Activity Score based on 28 joints including ESR; DAS28 CRP Disease Activity Score based on 28 joints including CRP
Of the 36 participants with RA, 81% were seropositive at baseline. Additionally, 49% of participants diagnosed with RA or SLE were ANA positive at the time of assessment (41% of RA; 86% of SLE patients). An analysis of ANA patterns and titres for patients with RA or SLE showed high frequencies of homogenous (60%) and speckled (73%) patterns with similar distributions of low (80, 160) and high (>=320) titres (41% and 59%, respectively). Past medication use for prevalent cases included non-biologic DMARDs (including methotrexate, plaquenil, sulfasalazine, leflunomide, azathioprine and mycophenolate mofetil) in 32% of patients ($n = 9/28$) and biologic DMARDs in 5 patients (18%). There were 4 patients (7%) taking oral steroids at enrolment to the cohort.

**Disease Activity at Initial Assessment**

The mean baseline HAQ was 1.35 ($SD = 0.71$) and the mean TJC28 and SJC28 were 8.7 ($SD = 7.7$) and 5.5 ($SD = 5.7$), respectively. Tender joint counts were higher but there were otherwise no differences in joint involvement, disease activity measures and patient-reported outcomes between incident and prevalent disease patients. Over 2/3’s of RA patients (72%) were in moderate or high DAS28 disease activity states at the initial visit.

*Follow-up duration.* A total of 374 visits were included in our analysis. Patients were followed for an average of 29 ($SD = 23$) months with an average of 6 ($SD = 5$) visits per participant and a mean of 6 ($SD = 6$) months in between consecutive visits. Eleven participants (19%) were lost to follow-up. *Disease activity and patient-reported outcomes over time.* With adjustment for baseline HAQ, age, gender, smoking, baseline SJC28, and baseline TJC28, swollen and tender joint counts significantly improved during follow-up (SJC28 monthly rate of change -0.20, 95%CI -0.29 to -0.10; TJC28 monthly rate of change -0.20, 95%CI -0.34 to -0.01; both $p < 0.01$). Although the swollen joint count based on 66 joints also demonstrated improvement (SJC66 monthly rate of change -0.31, 95% CI -0.46 to -0.16, $p < 0.001$), TJC68 did not improve over time. Pain, ESR, CRP, MD Global, and HAQ scores, and DAS28ESR and DAS28CRP scores for RA patients, also did not significantly improve over time (Table 2). Patient global evaluation score worsened over time. When comparing disease activity over time between patients with incident and prevalent IA conditions, ESR and CRP were observed to improve at a slower rate for patients with incident disease (slope difference ESR 0.21, 95%CI 0.01 to 0.41, $p=0.04$; slope difference CRP 0.02, 95%CI 0.01 to 0.03, $p < 0.01$), whereas there were no differences in rate of change in the other disease activity measures between prevalent and incident cases (Table 2).
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Crude Slope (95% CI)</th>
<th>Adjusted Slope *</th>
</tr>
</thead>
<tbody>
<tr>
<td>DAS28 ESR</td>
<td>-0.45 (-0.09 to 0.01) * p = 0.06</td>
<td>-0.04 (-0.09 to 0.01) * p = 0.15</td>
</tr>
<tr>
<td>DAS28 CRP</td>
<td>-0.03 (-0.08 to 0.03) * p = 0.38</td>
<td>-0.02 (95% CI -0.07 to 0.04) * p = 0.60</td>
</tr>
<tr>
<td>Erythrocyte Sedimentation Rate</td>
<td>-0.16 (-0.46 to 0.15) * p = 0.31</td>
<td>-0.28 (95% CI -0.59 to 0.02) * p = 0.070</td>
</tr>
<tr>
<td>C-Reactive Protein</td>
<td>-0.01 (-0.03 to 0.02) * p = 0.68</td>
<td>0.01 (95% CI -0.01 to 0.03) * p = 0.42</td>
</tr>
<tr>
<td>Health Assessment Questionnaire</td>
<td>0.01 (-0.01 to 0.01) * p = 0.72</td>
<td>0.01 (95% CI -0.01 to 0.01) * p = 0.45</td>
</tr>
<tr>
<td>Patient Global Evaluation Score</td>
<td>0.08 (0.03 to 0.13) * p &lt; 0.01</td>
<td>0.08 (95% CI 0.03 to 0.13) * p = 0.002</td>
</tr>
<tr>
<td>Physician Global Evaluation Score</td>
<td>-0.04 (-0.09 to 0.01) * p = 0.15</td>
<td>-0.05 (95% CI -0.11 to 0.06) * p = 0.078</td>
</tr>
<tr>
<td>Pain</td>
<td>0.013 (-0.032 to 0.057) * p = 0.58</td>
<td>0.01 (95% CI -0.05 to 0.05) * p = 0.97</td>
</tr>
<tr>
<td>Tender Joint Count (/28)</td>
<td>-0.19 (-0.31 to -0.07) * p &lt; 0.01</td>
<td>-0.20 (95% CI -0.34 to -0.06) * p &lt; 0.01</td>
</tr>
<tr>
<td>Tender Joint Count (/68)</td>
<td>-0.26 (-0.47 to -0.05) * p = 0.01</td>
<td>-0.22 (95% CI -0.45 to 0.02) * p = 0.07</td>
</tr>
<tr>
<td>Swollen Joint Count (/28)</td>
<td>-0.18 (-0.27 to -0.09) * p &lt; 0.01</td>
<td>-0.20 (95% CI -0.29 to -0.10) * p &lt; 0.01</td>
</tr>
<tr>
<td>Swollen Joint Count (/66)</td>
<td>-0.29 (-0.43 to -0.15) * p &lt; 0.01</td>
<td>-0.31 (95%CI -0.46 to -0.16) * p &lt; 0.01</td>
</tr>
</tbody>
</table>

Note: *Adjusted for baseline health assessment questionnaire score, age, gender, smoking status, baseline swollen joint count (28 joint count), and baseline tender joint count (28 joint count)

**Treatment strategy.** Treatment was declined at the time of recommendation at only 3% of visits (n = 11/374), with the current treatment plan maintained at 63% and therapy tapered at 4% of visits. New non-biologic DMARDS and biologic DMARDs were prescribed at 34% and 13% of visits respectively. Steroid injections (intra-muscular, intra-articular or soft tissue) were provided at 21% of visits. The treatment reported at follow-up visits (n = 315) included crystal arthritis treatment (2%), non-biologic DMARD monotherapy (21%), non-biologic DMARD combination therapy (24%), biologic DMARD monotherapy (6%) or biologic DMARD in combination with non-biologic DMARD (6%), oral steroids (10%), or anti-inflammatories (18%). At 14% of follow-up visits, the patients had not initiated recommended therapy, or had discontinued therapy at their discretion.

A total of 196 visits for RA occurred, of which 115 had data available to calculate disease activity state using either the DAS28ESR or DAS28CRP (71 of 81 visits without a calculable DAS28 score were related to missing inflammatory marker results). Remission was documented at 17%, low disease activity at 19% and moderate or high disease activity at 64% of visits. Treatment was escalated with a biologic or non-biologic DMARD at 65% of visits where the patient was in moderate or high disease activity (n = 48 of 74 visits). Reasons for not escalating therapy with a biologic or non-biologic DMARD included initial visit status and baseline labs/investigations pending (n = 5), being too soon to assess response to a new therapy (n = 4), patient declining a therapy recommendation (n = 3), having a contraindication to therapy (n = 1), or physician-decision driven by the lack of swollen joints on assessment (n = 10) or opting to provide an intra-articular injection to a single swollen joint (n = 2). In a single case the current therapy was maintained despite active disease. There were no differences in
escalation between incident and prevalent RA groups where RA patients were in moderate or high disease activity state ($p = 0.7$).

**Discussion**

We present effectiveness data from a model of care consisting of specialized rheumatology services embedded within the primary care home for an on-reserve First Nations community in Alberta. This model is designed to improve access to diagnosis and ensure sustained follow-up in keeping with established early and targeted treatment paradigms associated with improved inflammatory arthritis outcomes (Nam, 2016; Nell et al., 2004). Our model has had to balance the intake of patients with active disease that are prevalent cases, along with assessment and diagnosis of new patients who may or may not have inflammatory arthritis. Although there is no direct comparison possible for the level of access to rheumatology services existing before our model was established, we feel that the model is effective in ensuring access as evidenced through both the number of incident cases diagnosed, and a large volume of prevalent rheumatic disease patients returned to care, with a less than 20% loss to follow-up rate. This suggests an improvement to a barrier to care that patients may have previously experienced.

As evidenced by the disease activity at cohort inception there was a large unmet burden for both established and new IA cases as evidenced by a high percentage of individuals in moderate or high disease activity states (for RA cases), high swollen and tender joint counts as well as HAQ scores, and a paucity of those with prevalent arthritis being on therapy. Tender and swollen joints were observed in small, medium and large joints indicating the potential for a wide-spectrum of functional impairment. Patients showed significant improvements in these joint counts over the course of the study and treatment was escalated following the Treat to Target strategy with a relatively small proportion of patients electing to not pursue or discontinue therapy. It is interesting to note that there were no differences in rates of change in disease activity measures between prevalent and incident cases, though this is possibly due to the fact that those determined to have incident disease may have had a long symptom duration prior to presentation for diagnosis; unfortunately it is a limitation of the dataset that symptom duration at inception to the cohort was not collected.

Despite the suggested improvements in access and reductions in disease activity, we did observe an increase in patient global score and no significant improvements in other patient-reported outcomes over the duration of the study. The increase in patient global score may be attributable to arthritis progression, but also the various factors affecting health status beyond arthritis including but not limited to psychological distress, reduced mental health status (Euesden et al., 2017), and the impact of other medical comorbidities (Nikiphorou et al., 2016). Further, we have investigated these results through qualitative inquiry which will be presented in a future paper. In brief, the biomedical model, of which our program is an example, is not sufficient to meet the patient’s emotional or spiritual needs, nor repair inequities that exist in the broader consideration of social determinants of health. Additionally, availability of patient support groups may be an integral part of treatment (Baker et al., 1996) but were
not being offered in the community until recently. As such, it is suggested that it is necessary to address the social environments which play a role in affecting patient outcomes, and integrate these considerations in program development and advocacy work.

There are few rheumatology centres in Canada with clinical and research collaborations with First Nations populations, and this study was facilitated by the internal resources and strategic plan of a community recognized for innovations in health service delivery on the reserve. Our study contributes new knowledge to a prevalent and pressing issue in rheumatology care, and provides insights into how to enhance health service models to ensure that Indigenous communities in Canada receive adequate and accessible rheumatology care. Although efforts were taken to address limitations in this study, some still remain. Of particular importance is the proportion of participants who were lost to follow-up. These patients were not able to contribute information on whether they sought care elsewhere or made a decision to not pursue western medicine paradigms. These results may be mediated by many factors but we endeavour to seek ongoing feedback from the community and patients to mitigate further loss to follow-up. Further, there was only one rheumatologist who provided care for the entire duration of the study. A physician’s experience in working with Indigenous communities and cross-cultural competency are not only assets but may be requirements to providing culturally-sensitive healthcare especially in a system with a legacy of racism towards Indigenous patients. It is also important to take note of the importance of allied health professionals and other community-health partnerships that must work in conjunction towards improving patient health. Additionally, our study only assessed one aspect of evaluation of a model of care: effectiveness at the patient-level. Ongoing evaluation of patient-level, provider-level and system-level outcomes are necessary (Dziedzic, French, Davis, Geelhoed, & Porcheret, 2016) and are in progress (Barber, accepted). We address how this model of care can address the population of a particular Indigenous community but future studies should investigate the generalizability of such models of care in other communities.

Conclusions
Evaluation of the effectiveness of a model of care for patients with inflammatory arthritis implemented in a First Nations community highlighted areas for further improvement. Despite improvement in swollen and tender joint counts, patient-reported outcomes did not significantly improve during follow-up and gaps remain in meeting relevant outcomes.

References


