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Community Setting as a Determinant of Health for Indigenous Peoples Living in the Prairie Provinces of Canada: High Rates and Advanced Presentations of Tuberculosis

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Community Setting as a Determinant of Health for Indigenous Peoples Living in the Prairie Provinces of Canada: High Rates and Advanced Presentations of Tuberculosis

Abstract

Indigenous Peoples in Canada experience disproportionately high tuberculosis (TB) rates, and those living in the Prairie Provinces have the most advanced TB presentations (Health Canada, 2009). The community settings (i.e., urban centres, non-remote reserves, remote reserves, and isolated reserves) where Indigenous Peoples live can help explain high TB rates. Through qualitative description, we identify how community setting influenced Indigenous people's experiences by (a) delaying accurate diagnoses; (b) perpetuating shame and stigma; and (c) limiting understanding of the disease. Participants living in urban centres experienced significant difficulties obtaining an accurate diagnosis. Reserve community participants feared being shamed and stigmatized. TB information had little impact on participants' TB knowledge, regardless of where they lived. Multiple misdiagnoses (primarily among urban centre participants), being shamed for having the disease (primarily reserve community participants), and a lack of understanding of TB can all contribute to advanced presentations and high rates of the disease among Indigenous Peoples of the Prairie Provinces.

Keywords

Canada, Indigenous Peoples, tuberculosis, misdiagnoses, community settings

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Community Setting as a Determinant of Health for Indigenous Peoples Living in the Prairie Provinces of Canada: High Rates and Advanced Presentations of Tuberculosis

Throughout the twentieth century, tuberculosis (TB) was considered the most significant health problem facing Canadians (Canadian Public Health Association, 2009; Public Health Agency of Canada, 2014; Wilkins, 1996). Improvements in living conditions and drug treatments in the second half of the twentieth century led to rapid declines in TB, now relatively rare among the general population (Public Health Agency of Canada, 2015). Today, TB can be quickly diagnosed, treated, and cured (Public Health Agency of Canada, 2015). A number of highly accessible TB educational resources also exist (Public Health Agency of Canada, 2014). However, Indigenous Peoples in Canada continue to experience disproportionately high TB rates (Public Health Agency of Canada, 2014, 2018). Indigenous Peoples comprise over 50% of active Canadian-born TB cases in the country (Long et al., 2013; Statistics Canada, 1992; Waldram, Herring, & Young, 2006). When compared to other parts of Canada reporting high incidence rates among Indigenous Peoples (for example, Inuit Nunangat), those living in the Prairie Provinces have the most advanced TB presentations (Health Canada, 2009; Long et al., 2013; Vachon, Gallant, & Siu, 2018). Through qualitative description, we explored how the community settings (i.e., urban centres, non-remote reserves, remote reserves, and isolated reserves) where Indigenous Peoples live can help explain the advanced presentations and high TB rates among Indigenous Peoples of the Prairie Provinces.

Determinants of TB

While the reasons for differences in incidence and progression of TB among Indigenous Peoples in various regions of Canada remain unclear, researchers have identified a complex array of factors that contribute to these disparities (Long et al., 2013). Among these potential explanations is the hypothesis that TB rates vary inversely with time since first contact with European colonizers (Enarson & Grzybowski, 1986). Although this position helps to explain differences in incidence rates between Eastern and Western Canada, it does not account for the heterogeneity observed across the Prairie Provinces (Long et al., 2013). On the prairies, TB rates increase in a West to East direction: lowest in Alberta and highest in Manitoba. Several factors related to community environment may help to explain this disparity, including access to health care, cultural sensitivity in health services, health care worker staffing and retention, public awareness of symptom recognition and stigma reduction, geographical isolation, socioeconomic conditions, housing quality and crowding, and discrimination (Cook, Enarson, & Buccholz, 2013; Government of Saskatchewan Ministry of Health, 2013; Long et al., 2013).

Access to Health Services

In Canada, access to health services differs among the community settings in which Indigenous Peoples live (i.e., urban centres, non-remote reserves, remote reserves, and isolated reserves) and is a significant determinant of health (Loppie Reading & Wien, 2009). Most Indigenous reserves, with the exception of a few located near urban centres, have on-reserve health services (Healy & McKee, 2004). In remote and isolated reserves (south of the 60th parallel), health services are provided through nursing stations and communities have limited and infrequent access to medical specialists, who tend to be flown in for short durations (Health Canada, 2015). However, challenges have been reported with the level of care and resources in these settings (Halseth & Ryser, 2006; Loppie Reading & Wien, 2009; Office of the Auditor

General of Canada, 2015). Nursing stations often face staff shortages and high staff turnover rates (Public Health Agency of Canada, 2013). Weather, proximity, and available transportation also make it difficult for those living in remote, isolated reserves to access health services off reserve, and community members often travel to urban centres to access health services (Halseth & Ryser, 2006; Public Health Agency of Canada, 2013).

Health services, particularly specialized services, may be more geographically accessible to Indigenous Peoples living in urban communities (Place, 2012). Yet, urban centre settings also pose their own set of challenges. In these settings, Indigenous Peoples may be unable to receive culturally sensitive health services (Adelson, 2005; Browne, 2005; Place, 2012; Sookraj, Hutchinson, Evans, & Murphy, 2012; Tang & Browne, 2008) and often experience overt racism, judgment, and discrimination (Denison, Varcoe, & Browne, 2014; Durey, Thompson, & Wood, 2012), which can result in unmet health needs (Tjepkema, 2002). Indigenous Peoples living in urban communities also commonly experience poverty, social exclusion, homelessness, and limited transportation as barriers to accessing health care (Place, 2012).

Indigenous Peoples living in different community settings (urban centres as well as non-remote, remote, and isolated reserves) experience varying levels of access and a range of barriers to appropriate health services (Health Canada, 2012; Loppie Reading & Wien, 2009; Marchildon, 2005). This reality is coupled with the disproportionately high TB rates among Indigenous Peoples, including those living in the Prairie Provinces with the most advanced TB presentations (Health Canada, 2009; Long et al., 2013; Vachon et al., 2018). Therefore, the objective of the present study was to understand how community setting may help explain the high rates and advanced presentations of TB among Indigenous Peoples in the Prairie Provinces.

Methods

The Determinants of Tuberculosis Transmission Project

This study is part of a larger multiple method seven-year research project, titled *The Determinants of Tuberculosis Transmission Among the Canadian-Born Population of the Prairie Provinces* (DTT Project; Boffa, King, McMullin, & Long, 2011). The DTT Project explored the environmental, biomedical, socio-cultural, and historical determinants of TB transmission. The research team was made up of social scientists, Indigenous health researchers, clinicians, and epidemiologists.

The DTT study protocol was presented to and approved in writing by all major Indigenous organizations on the prairies. This included the Network Environments for Indigenous Health Research, First Nations Inuit Health in Alberta, Federation of Saskatchewan Indian Nations and the Northern Inter-Tribal Health Authority in Saskatchewan, and the Centre for Aboriginal Health Research and the Assembly of Manitoba Chiefs in Manitoba. The project also received ethics approval from the Universities of Alberta, Calgary, Saskatchewan, and Manitoba, as well as Health Canada (Boffa et al., 2011). Consultative committees, named Provincial Network Committees, were established in each province, and they were composed of health professionals, Elders, traditional healers, Indigenous and government stakeholders, and former lived-experience TB patients. The Provincial Network Committees consisted of over 50% Indigenous Peoples and guided all aspects of the research, including interpretation of the data.

Table 1. Definition of Community Settings

Urban centre	Non-reserve areas with a population between 1,000 and 100,000 people or more (Statistics Canada, 1992)
Non-remote reserve	Located less than 350 kilometers from an urban centre (Health Canada, 2012)
Remote reserve	Located more than 350 kilometers from the nearest centre that has year-round road access (Health Canada, 2012)
Isolated reserve	Does not have year-round road access (Health Canada, 2012)

Participants were identified and recruited through medical professionals across the Prairie Provinces and had to be 15 years of age or older, born in Canada, and diagnosed with culture-positive pulmonary TB between 2007 and 2008. First, participants were invited to complete a questionnaire, which asked demographic questions (e.g., age, gender, occupation) and questions about their TB (e.g., prior infections, symptoms, where they received their diagnosis). Participants who completed a questionnaire and were sputum smear-positive (more infectious) were invited to participate in an interview ($n = 112$). After 56 smear positive participants were interviewed, data saturation was achieved and no subsequently-diagnosed cases were invited to participate. Written consent was provided by all 56 participants; parental consent was provided for participants under the age of 18 living with a parent or guardian.

From the 56 interviews, 48 were included in this analysis. Eight interviews were removed because they were from a very distinct urban community setting. In this urban community setting, Indigenous Peoples made up approximately 95% of the population¹ and there were significantly high rates of TB, along with high rates of violence, substance use, unemployment, and poverty, which made this setting dissimilar to the communities where the other 21 urban cases were derived. Consequently, these participants' TB stories were overshadowed by other pressing economic, health, and social issues in their setting, and including these interviews would have distorted the data and results. Researchers could partner with this community in the future to address the complex environment in which these Indigenous people live. Table 2 outlines demographic and behavioural characteristics for the participants included in the current study.

¹ Indigenous Peoples make up 4.9% of the total population in Canada (Statistics Canada, 2017).

Table 2. Demographic and Behavioural Characteristics of Participants by Community Type

Demographic and Behavioural Characteristics	Urban Centre (n = 21)	Non-Remote Reserve (n = 15)	Isolated or Remote^a (n = 12)	Total (N = 48)
Age (years)				
15-34	5	4	8	17
35-64	16	11	4	31
Sex				
Male	9	8	6	23
Female	12	7	6	25
Province				
Alberta	7	7	0	14
Saskatchewan	6	4	6	16
Manitoba	8	4	6	18
Marital status				
Single	8	6	5	19
Married or Common-Law	8	6	6	20
Separated or Divorced	5	3	1	9
Employment status				
Employed	5	6	5	16
Unemployed	16	9	7	32
Cigarette smoker				
Yes	14	12	10	36
No	7	3	2	12
Alcohol or substance use				
Yes	20	12	9	41
No	1	3	3	7
Regular family physician				
Yes	11	11	3	25
No	10	4	9	23

Note. ^a There were 10 participants from isolated communities and 2 patients from remote communities.

Data Collection and Analysis

A qualitative descriptive design was used to understand how community setting may help explain high rates and advanced presentations of TB among Indigenous Peoples in the Prairie Provinces. A qualitative descriptive design, as described by Sandelowski (2000, 2010), originates from an interpretive paradigm and draws on the “everyday language” of participants (Sandelowski, 2000, p. 336) to develop a

comprehensive, coherent, and useful “description and summary of the phenomenon” (Mayan, 2009, p. 53).

Semi-structured interviews were conducted, and interviews were recorded and professionally transcribed verbatim. Data collection and analysis were iterative. Data were analyzed among a five-member research team using qualitative content analysis (Mayan, 2009). Qualitative content analysis is a data analysis method for interpreting the content of text data “through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p. 1278). Given the descriptive nature of the study design, a conventional approach to content analysis was used where categories were derived directly from the data. Transcripts were first read in their entirety to develop an understanding of the content. The team then divided the transcripts by community setting (across the provinces) and subsequently re-read and reviewed the transcripts before beginning line-by-line coding. Data were managed and shared among team members through Atlas.ti 5.2 (Scientific Software Development GmbH, Berlin, Germany) and numerous face-to-face and on-line analytic discussions occurred. Finally, similar codes were grouped into categories, and descriptions of these categories were created and evaluated to determine internal and external homogeneity (Mayan, 2009). At this stage, and according to category, the experiences that were similar across community settings were merged and are discussed together. The results are conceptual descriptions (Sandelowski & Barroso, 2003) that may assist decision-makers and clinicians in understanding how community setting may help explain high rates and advanced presentations of TB among Indigenous Peoples. Members of the Provincial Network Committees contributed to the evolving analysis and verified the results.

Findings

The community setting (i.e., urban centre, non-remote reserve, remote reserve, or isolated reserve) participants lived in at the time of diagnosis heavily influenced participants’ TB experiences. Community setting may help explain the high rates and advanced presentations of TB by (a) delaying accurate diagnoses; (b) perpetuating shame and stigma; and (c) limiting understanding of the disease.

Delayed Diagnosis

Urban and non-remote reserve participants commonly reported seeking diagnoses through walk-in clinics and hospital emergency rooms, while participants from remote and isolated reserves described visiting their local nursing stations or having nurses come to their homes. The community setting either helped participants obtain treatment relatively quickly, as in the case of remote and isolated reserve settings or, as in the case of urban and non-remote reserve settings, it led to participants returning to health professionals repeatedly due to misdiagnoses and deteriorating health. The delayed diagnoses and, ultimately, delayed treatment often experienced by Indigenous Peoples living in urban and non-remote reserve settings may help explain the high rates and advanced presentations of TB among Indigenous Peoples living in the Prairie Provinces.

(i) Urban centre and non-remote reserve community settings. A significant frustration noted by several participants from urban centres and non-remote reserves was that they lacked a consistent family physician and consequently relied on walk-in clinics and hospital emergency rooms. Nearly half of urban participants did not have a regular family physician (see Table 2). While the majority of non-remote

reserve participants did report having a regular family physician, the interviews indicate that many were not making use of their physicians.

Participants largely described their experiences of seeking diagnoses through walk-in clinics and hospital emergency rooms negatively. The following comment illustrates the dismissive treatment experienced by some participants in walk-in clinics and hospital emergency rooms:

He said, "You should go see your family doctor. This is for emergencies." I said, "Doesn't this sound like an emergency? It took me three times to come in here and you guys couldn't prescribe anything right for me. There's something going on here. First you guys told me it was bronchitis, now it's pneumonia . . . You're the third different doctor that I've seen in emergency . . ." And he said "Yeah, well go see your own doctor next time." (Alberta, Non-Remote Reserve)

While participants presented with symptoms commonly associated with TB, including "night sweats," "chills," "coughing up phlegm," "a loss of energy," and "losing weight", and sometimes more extreme symptoms such as "collapsing," "losing bowel control," and "feeling like [they were] gonna die," they often received inaccurate diagnoses. Many times, participants were told that they likely had "pneumonia," "bronchitis," or a "chest infection." Overall, participants explained that doctors would listen to their chest, possibly order a chest X-ray, and subsequently prescribe them with unnecessary medications. The desire to gain an accurate diagnosis and the fear of dying had patients returning to the same walk-in clinics and emergency rooms multiple times. Often it was the participant who had to continue advocating for a diagnosis, or mention TB, for doctors to administer the appropriate tests. One patient stated that he saw approximately four different doctors at the same walk-in clinic before receiving an accurate diagnosis:

I went to the Medi-Centre . . . where I usually go and I saw, I don't know how many different doctors there . . . my . . . sickness was progressing . . . I kept going and I even came to a point asking them if they can check my phlegm . . . I was terrified so the doctors kept telling me that nothing was wrong with me. Finally, this one doctor, right away, even before he examined me, he gave me paper towel to cover my mouth. Right away he knew. (Alberta, Urban Centre)

In addition to misdiagnoses, many of the participants who sought a diagnosis in urban centres believed that doctors viewed them as attempting to abuse prescription medication. One participant noted:

I kept going to the doctor. I kept going to walk-in clinics because . . . I just felt like I had the flu all the time, and then my doctor thought it was the flu, and then of course I'd been taking Tylenol all the time and if I knew I was gonna run out by the weekend, I'd go to the walk-in clinic. And then they kinda looked at you, kind of funny like, "Oh you know, you're coming here for Tylenol." (Saskatchewan, Urban Centre)

Many participants also believed that, when they accessed urban health services, they were met by doctors who were indifferent and did not take their concerns seriously. One participant felt that it took a drastic health change for the doctors to believe he was sick:

I didn't know what it was, like I thought it was pneumonia the first time . . . I went to the hospital and nothing happened . . . Finally, after so many times, trips to the hospital I finally see a doctor who said, "There's something wrong with you." I lost 50 pounds you know. (Alberta, Non-Remote Reserve)

Many participants felt frustrated, believing that health professionals need to be more accountable. One participant explained:

Somebody has to be reprimanded for misdiagnosing people . . . It's probably other people it's happened to . . . because you can't go around misdiagnosing people . . . and thinking that they've just got a cold or, he said to me, "It could be a touch of pneumonia." Then I went, I just have to bundle up a little better when I work, that's all. Take more cough medicines, and then it never did get better. I just got worse. (Manitoba, Urban Centre)

Another participant acknowledged that doctors may lack knowledge about TB and that there was a need for further training. She believed that this would help to ensure that others do not experience multiple misdiagnoses, as she had:

Well the thing is, like even the doctors, they're not totally aware of TB themselves. Maybe I wouldn't have been sick so long if the doctors had checked out right from the beginning, when I said I had no energy. (Saskatchewan, Urban Centre)

While most experiences shared by urban and non-remote reserve participants seeking a diagnosis were negative, there were a few who spoke about positive experiences in an urban setting. In two urban centres, in two separate provinces, there are health centres that serve large Indigenous populations. One participant spoke of seeking a diagnosis in one of these health centres, which he frequented regularly, and where he was immediately given a sputum test after talking to a doctor. This story was similar for a woman living in an urban centre who would commonly access her inner-city health centre. She stated that because they knew her, they had observed her health deteriorate and she received an accurate diagnosis.

(ii) Remote and isolated reserve community settings. The participants from remote and isolated reserves accessed their local nursing stations when they were ready to seek a diagnosis for their symptoms. While it was noted by one participant that "people in smaller communities have no access to doctors" and that seeing a doctor typically involved a lengthy referral process, community health nurses were invaluable in providing necessary services. The remote and isolated reserve participants reported relationships with local nurses, as described by one participant:

This health nurse . . . she works for the nursing station for a long time now, over 30 years now, 20 years . . . every time she sees me then she will just, talk to me even when I feel sad.
(Saskatchewan, Isolated Reserve)

Another participant described the friendship he had formed with the nurses in his community:

We used to know the nursing station staff by name . . . They'd come over unannounced. They would just walk in and sit down, grab a cup of tea. They were our friends. We would take them fishing in the summer time. (Manitoba, Isolated Reserve)

The access to and relationships with local nurses and other employees in the nursing station resulted in quick diagnoses. Participants explained that they were given Mantoux tests, sputum tests, and chest X-rays after seeing a nurse. One participant noted that he had gone “to the nursing station and they just found out right away.” In another case, a young girl who had been experiencing chest pain went to the nursing station and had a chest X-ray. She was then medivaced² out of her community to a nearby urban hospital to receive treatment. While the results of a sputum sample typically took one or two days to be returned, a nursing station staff member would follow up with participants when their results were available. For the isolated and remote reserve participants, there were few examples of misdiagnoses and prescriptions for antibiotics.

Shame and Stigma

Shame and stigma experienced after receiving a TB diagnosis may also contribute to the high rates and advanced presentations of the disease among Indigenous Peoples by deterring individuals from seeking medical attention and treatment. Participants described a host of negative feelings about returning home after being diagnosed with TB, including shame, stigma, others' fear of contagion, and concerns over a lack of confidentiality. Although shame over their TB diagnosis was a feeling expressed by many participants, regardless of where they lived, descriptions of stigmatization and a lack of confidentiality were more prominent among participants who lived on reserves.

(i) Non-remote, remote, and isolated reserve community settings. Participants living in reserve communities expressed sadness knowing that others in their communities would treat them differently because they had TB. Many participants described feeling “embarrassed,” “ashamed,” and “disappointed” over receiving a TB diagnosis. One participant expressed that she was “hoping for something else” as:

People in [my community], when they hear the word “TB” they're all “oooo... Oh my God” . . . cause they are afraid of TB . . . They're scared they might catch it too, I guess. (Manitoba, Isolated Reserve)

Participants often believed that their friends and community members would distance themselves from them over fears of catching the disease. One participant explained that news about her TB diagnosis had “spread already,” and that she was going to “hide [her] face” and “not go out” when she returned home. Another participant was worried that “people [would] be scared to be around [her],” and stated that she had to “isolate” herself when she returned home. A participant from Saskatchewan who, at the time of her interview, had returned home from her treatment, said that people were making comments such as, “Don't go by her.” Another participant noted that when word spread about his diagnosis, his coworkers refused to work with him.

² Medivac is the term for an emergency medical evacuation of a patient.

These experiences of shame were explained as ignorance by one participant who was flown out of his community for treatment:

The pilot told me to sit in the chair at the back . . . And he said, “Now don’t touch anything.” He wouldn’t handle my bag. I tried to give him my travel warrant . . . he held out a paper bag to me and said, “Put it in there” . . . He was scared . . . I wasn’t too comfortable with that. Not because of what I have but because of his ignorance, I would say. (Manitoba, Isolated Reserve)

In addition to feelings of shame and stigma, participants also voiced concerns about the confidentiality of their diagnosis. Participants spoke about certain families in the community being granted the privilege of privacy, while others did not receive the same consideration:

[I]t’s [TB diagnosis] supposed to be confidential and there’s nothing confidential. Everybody knew I had TB. Everybody knew I was getting tested . . . I just recently found out that this one certain family is riddled with TB and nobody has heard a word about that, whereas just because of my last name, I’m on a lower class scale and everybody had heard that and then there’s even poorer people than me and my family name and everybody hears all about them. (Saskatchewan, Non-Remote Reserve)

One of the participants linked the lack of confidentiality to being in a small community where “people talk.” She further expressed fear that if her family turned away from her as well she “would have nowhere to go.”

Limited Understanding of TB

Finally, limited understanding of TB may influence disease rates and progression among Indigenous Peoples living in the Prairie Provinces. Participants described varying degrees of available TB information and knowledge depending on their community setting. In this instance, reserve community participants (non-remote, remote, and isolated) had different experiences than those living in urban centres.

(i) Non-remote, remote, and isolated reserve community settings. Community health centres and nursing stations served as a central point of information sharing. Through frequent community health meetings, health professionals brought together a large number of people to talk about health concerns impacting their communities. As an example, one participant who had moved into an urban centre acknowledged that his home reserve had taken on the task of gathering people for meetings:

I don’t think, well nowadays it’s not hard to deal with it [TB] because there’s help and back home they have a lot of support too, like they’ll have meetings once a month in the town hall and everybody will go there to pray. (Saskatchewan, Urban Centre)

In addition, a number of participants noted exposure to TB information through posters and pamphlets located in community spaces such as health centres. Many of the participants from remote and isolated reserves also spoke about TV and radio broadcasts that highlighted health topics and encouraged individuals to visit a health professional if they were presenting with TB symptoms. One participant explained:

The information is there . . . Talks were given by public health nurses . . . and I know the information is at the nursing station which hands out pamphlets, and nurses used to have once-a-week, a show on local TV where people call in. (Manitoba, Isolated Reserve)

Regular testing was also set up in reserve communities to try to diagnose as many people as early as possible. It was because of this routine testing that one participant was diagnosed with TB prior to experiencing symptoms:

I didn't even have any symptoms at all, until the X-ray team came . . . I saw my auntie sitting there and they were still doing chest X-rays so I said to myself, "I go there get this done while I'm in here," otherwise I probably wouldn't have done it. (Manitoba, Isolated Reserve)

However, having TB information available did not necessarily contribute to participants seeking a diagnosis sooner. As one participant stated, "in the community it is not the lack of information" that causes TB to persist. Some participants explained that although workshops were offered in their communities, gathering people together to talk about illnesses was difficult and turnout was often low:

They do workshops on it, but . . . very few people go because they either . . . have jobs and they can't go, and some are elderly and can't walk or leave their house. (Alberta, Non-Remote Reserve)

Another participant felt that the workshops needed to be promoted more effectively:

I've never sat and listened to information sessions on anything. Like where a qualified person comes in and says, "Here's what TB is all about" . . . and if they did it, it was not very well advertised. There's gotta be something done. It's gotta be implemented in the schools or compulsory, something. There's gotta be more education. (Saskatchewan, Non-Remote Reserve)

Furthermore, some participants explained that available TB information could be hard to understand. One of the participants had seen a TB poster in her community health centre but was still confused about the illness. This was expanded on by another participant who noted, "I went to the meetings and they would talk about TB and my attitude was 'well I'll know when I get it.' I think that's how most of the people are." Nonetheless, some participants explained that the availability of TB information was not at the heart of the problematic TB rates. Despite having information about TB, a number of participants acknowledged that community members continue to hold negative and inaccurate perceptions about TB.

(ii) Urban centre community setting. In contrast to reserve participants' experiences, urban participants reported a lack of information and knowledge on TB. One participant emphasized the importance of having more education accessible in all health services facilities, and not just in TB clinics. Many participants also expressed the need for increased TB information, not only for those affected, but for the general public as well. One participant explained that because she was not able to identify the illness in others, she became infected with TB:

TB is not a very glorious disease. I had no idea how bad it was. Education doesn't educate those who are not sick how to look after people who are sick . . . So education is not only improving the well-being of a person in bad health but it's, you know, pro-active, prior intervention for people who don't wanna get sick or for people who want to properly care for people who are sick. (Saskatchewan, Urban Centre)

Other participants lamented the gap between younger generations and their elders. One participant, who had grown up on a northern Saskatchewan reserve where TB was more prevalent, explained that there was a common disinterest in TB information by younger generations:

The young people, they seem to brush it off . . . But the old people are, it's almost mythological, how deadly it is, you know. They always make it like a third person. The sickness. It'll come and get you or whatever . . . Because it's out lurking around there. (Alberta, Urban Centre)

For participants from urban centres, a lack of TB knowledge, whether through a dearth of available information or disinterest in learning about the disease, was thought to greatly impact individuals' capacities to recognize TB symptoms. During the interviews, many participants expressed surprise that TB was still a problem and were unaware that they could become infected. These participants highlighted the need to expand the availability of TB information so more members of the general public could recognize symptoms in others.

Discussion

Findings from the current study demonstrate that the community setting Indigenous Peoples live in can play an integral role in: When people are diagnosed, their hesitation in seeking a diagnosis, and the TB information that is available to them. Delays in diagnosis, being shamed by community members, and limited understanding about the disease can all help explain the high rates and advanced presentations of TB among Indigenous Peoples in the Prairie Provinces.

Postcolonial theory can also help explain, and make obvious, Indigenous Peoples' experiences by taking the issue of race as a lens through which we can understand the effects of European colonization and the effects of the colonizer on the colonized. In a colonial environment, saturated by inequality, power, and domination (Downing & Kowal, 2011), race is used in the colonizing process to dictate and structure Indigenous Peoples' lives, life opportunities, and identity, as well as their health and well-being. By invoking postcolonial theory, we can begin to understand—through the communities in which Indigenous Peoples live—how racism and indifference toward Indigenous Peoples plays into delayed diagnoses, how shame has been internalized and stigma used to perpetuate Indigenous identities as being poor and lacking self-care, and how information alone cannot change the course of a disease that is entrenched in colonial perceptions and practices.

Below we draw heavily on health sciences literature to provide the foundation for needed changes in policy and practice—targeted according to community setting—that will address the high rates and advanced presentations of TB among Indigenous Peoples in the Prairie Provinces. We start with summarizing the findings in Table 3.

Table 3. Content Analysis Categories Across Community Settings

Category	Urban Centre	Non-Remote Reserve	Remote Reserve	Isolated Reserve
Delayed diagnosis	Participants accessed emergency rooms and walk-in clinics. They were often misdiagnosed and often experienced discrimination. Even if participants reported having a regular family physician, many still relied on emergency rooms and walk-in clinics.		Participants accessed nursing stations where they were familiar with nursing staff, received immediate TB testing and a quicker diagnosis.	
Shame and stigma	Participants had strong feelings of shame, sadness, and fear over returning home and being stigmatized by community members, family, and friends. Confidentiality of diagnosis is a large concern for participants in reserve settings.			
Limited understanding of TB	Limited TB information available.	Some TB information is available at community health centres and at community meetings, but attendance is low.	There are varying degrees of TB information available at nursing stations through TB posters, pamphlets, and charts. Community radio and television stations broadcast TB information and information sessions provided.	
				There is a lack of discussion about TB. There is a need for information so people can protect themselves against TB or care for ones that are infected.

Delayed Diagnosis

When accessing health services in urban centres, participants described overwhelmingly negative experiences. Urban and non-remote reserve participants shared their experiences of repeatedly visiting hospital emergency rooms and walk-in clinics, seeing multiple health professionals (who they viewed as indifferent, lacking diagnostic skills, and discriminatory), being administered various medical exams unrelated to TB, being misdiagnosed multiple times, and being prescribed unnecessary medications.

In the current study, not having a family doctor or not seeking care from a family doctor helped explain urban and non-remote reserve participants' reliance on hospital emergency departments or walk-in clinics as primary sources of health care. These experiences correspond with those of urban Indigenous Peoples in a study by Browne et al. (2011), who reported relying on emergency departments due to barriers (e.g., discrimination, judgement, dismissal of concerns, transportation) to accessing other primary care providers, such as family doctors. However, paradoxically, participants in the study by Browne et al. (2011) often described similarly dissatisfying experiences at emergency departments. In another study, Tang and Browne (2008) found that many Canadians and health professionals believed that Indigenous Peoples overused the emergency room for primary health needs, and they were abusing

the health care system to access drugs. Regardless of where urban Indigenous Peoples seek care, they often experience discrimination and dismissal of their health concerns.

Due to their heavy reliance on emergency rooms and walk-in clinics, urban and non-remote reserve participants also lacked relationships with health care professionals and continuity of care. Continuity of care is less likely in walk-in clinics and emergency rooms than with a regular family physician (Howard et al., 2008), and numerous studies have evidenced the importance of continuity of care for positive health outcomes (Hjortdahl & Laerum, 1992; Pereira Gray, Sidaway-Lee, White, Thorne, & Evans, 2018). Related to a lack of continuity of care, the use of walk-in clinics and emergency rooms may also result in repeat visits for the same concern (Howard et al., 2008). In a systematic review of 58 studies addressing delay in diagnosis and treatment of TB, Gundersen Storla, Yimer, and Bjune (2008) identified a cycle of repeated visits to health care providers as a core contributor to delayed diagnosis of the disease.

Accurate and timely diagnosis of TB requires appropriately trained medical professionals and the availability of diagnostic facilities (Gundersen Storla et al., 2008). Although urban health care providers in the present study had access or could refer to diagnostic services, they often did not request the appropriate diagnostic tests. Health care providers working in urban communities may not have the necessary education and experience to diagnose and treat TB (Gundersen Storla et al., 2008; Long, 2006).

Experiences of participants from remote and isolated communities seeking a diagnosis were in direct contrast to most participants from non-remote reserves and urban centres. Counterintuitive to what one might expect given the vast disparities in health care resources and personnel compared to urban areas, participants living on remote and isolated reserves received quicker and more accurate diagnoses due to their access to and relationships with knowledgeable local nurses. Not only did these participants experience continuity of care, but also a culturally safe environment critical to improving health outcomes for Indigenous Peoples (Durey et al., 2011; World Health Organization, 2006).

Implications for policy and practice for urban and non-remote reserve communities. We identify three areas to address diagnostic delays in urban and non-remote reserve communities. First, we need to address how systematic racism is shaping the health care experiences of Indigenous Peoples. The guidelines document, *Health and Health Care Implications of Systematic Racism on Indigenous Peoples in Canada*, developed by the College of Family Physicians of Canada's (2016) Indigenous Health Working Group, is a direct response to the recommendations in the Truth and Reconciliation Commission of Canada (2015) report. This document suggests actions to start addressing the enduring health inequalities experienced by Indigenous Peoples, which should be taken-up by all new and established physicians in Canada. Second, health care professionals working with Indigenous patients in urban settings where TB is less common should be taught to consider TB high on the differential diagnosis in Indigenous patients that present with respiratory and/or constitutional complaints, particularly those that are subacute or chronic.

Third, services that specifically support Indigenous Peoples open possibilities for consistent and appropriate care for the health needs of Indigenous patients, which can circumvent the high rates and advanced presentations of TB. It is possible to attain the locally focused practice characterizing remote and isolated reserves in urban settings. Just like urban participants in the present study who accessed

health centres that largely served Indigenous populations, Macdonald, Rigillo, and Brassard (2010) found that urban Indigenous participants who accessed their local Native Friendship Centre had more positive experiences with health services and viewed their relationships with health professionals more positively. Health care professionals interested in working with urban Indigenous communities with a willingness to build provider–patient relationships and culturally safe environments need to be identified and supported.

Shame and Stigma

Tuberculosis has been viewed as a dirty disease, only affecting the poor, the lower class, and those lacking self-care (Courtwright & Norris Turner, 2010; Juniarti & Evans, 2011; McEwen, 2005). The stigma experienced by participants living on reserves led to feelings of shame and guilt that caused them to isolate themselves from others. These experiences are echoed by Atre, Kudale, Morankar, Gosoniu, and Weiss (2011), who found that community members were fearful of sharing utensils with TB patients or eating TB patients' food due to concerns of contagion. Some people may also not seek a diagnosis if they witness others experiencing shame, stigmatization, and violation of confidentiality. For those living in small reserve communities, seeking a diagnosis can mean taking a significant risk with respect to one's reputation. Consequently, shame and stigma represent significant barriers to seeking medical care, which can result in diagnostic delays that further contribute to high rates and advanced presentations of TB. This highlights the importance of addressing the shame, stigmatization, and lack of confidentiality experienced by many Indigenous Peoples living on reserves.

Implications for policy and practice for reserve communities. To address diagnostic delays related to shame and stigma in reserve communities, we draw on work by Long et al. (2012) that promotes the involvement of Elders and youth, the latter through the school system and their curricula, as ways forward to break down stigma. Promoting educational activities that involve survivors of TB may be especially important for destigmatizing the infection (von Delft et al., 2015).

Limited Understanding of TB

Access to TB information has been widely studied as critical in reducing the spread of the illness (Demissie, Lindtjorn, & Berhane, 2002; Gele, Bjune, & Abebe, 2009; Melaku, Sharma, & Alemie, 2013). The majority of studies in this area have been conducted in Africa, where it was found that a lack of TB knowledge coincided with proximity to adequate services (Demissie et al., 2002; Gele et al., 2009). Due to the remoteness of many African communities, medical information is often sparse, which impacts citizens' knowledge about TB. Lienhardt (2001) also found that lack of TB awareness and knowledge significantly impacts TB transmission rates. However, in the current study, proximity to health services was not a significant factor in access to TB information or the subsequent impact on participants' level of TB knowledge. All the participants in this study were in proximity to different types of health services (e.g., hospitals, nursing stations). The availability of TB information varied across community settings and participants remained confused about TB, regardless of community setting.

Implications for policy and practice for reserve communities. To improve TB information and education, we suggest using more innovative methods that are effective in reaching target audiences. The use of proactive health campaigns in the fight against TB is supported by Alvarez et al. (2014), who used a TB health campaign to encourage individuals living in Nunavut to get tested. Efforts to improve

individuals' understandings of TB should be prioritized according to TB prevalence in communities, as communities vary with respect to the burden of TB. Along with providing accurate and relevant TB information, the most effective form of early TB diagnosis may be to establish routine testing in high-incidence communities.

Overall implications for better TB treatment across all communities. Delivering TB information and education effectively and appropriately is also critical in fighting stigmatization and addressing diagnostic delays. Previous research has shown that poor knowledge about TB can impact patients' attitudes about the disease, and that stigma can impact health seeking behaviour (Abebe et al., 2010; Courtwright & Norris Turner, 2010; Tolossa, Medhin, & Legesse, 2014). Policy and practice need to change to enable health care providers to provide better information and education that will improve knowledge about and destigmatize TB. This will require shifting the current inordinate focus on treatment to give greater priority to public health programs and prevention (Menzies, Lewis, & Oxlade, 2008).

While TB has historically been constructed as a social disease that requires social, economic, and environmental interventions, current efforts to manage the disease tend to focus on medical interventions (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). In Canada, TB-related expenditures disproportionately emphasize treatment, with only 40% allocated to prevention and control activities (Menzies et al., 2008). This is reflective of Canada's health system overall, which has been described as taking a reactive approach to health (MacIntosh, Rajakulendran, Khayat, & Wise, 2016). Funding for public health, including activities related to health promotion and disease prevention, comprises a small proportion of total national health expenditures, standing at only 5.5% in 2017 (Canadian Institute for Health Information, 2017). Greater investment in public health efforts that address social determinants and promote early detection in at-risk populations are needed to reduce the burden of TB among Indigenous populations (Lönnroth et al., 2009; Menzies et al., 2008). This includes addressing the root causes of the disease through strategies designed to reduce poverty and improve living and working conditions (Lönnroth et al., 2010).

Conclusions

This study presents the realities of Indigenous Peoples' experiences in accessing health services for a TB diagnosis. Participants who sought a diagnosis in an urban centre had difficulties obtaining an accurate diagnosis when relationships between health professionals and patients were not established. Urban participants reported feeling discrimination from health professionals who may not have been fully educated around the illnesses affecting Indigenous Peoples, causing them to miss opportunities to correctly diagnose TB, and thereby potentially contributing to the advanced presentations and high rates of TB among Indigenous Peoples. Participants from remote and isolated reserves reported far fewer barriers in receiving a TB diagnosis, predominantly due to the relationships between community health nurses and community members. However, participants from reserves reported more shame, stigmatization, and concerns regarding a lack of confidentiality than did participants from urban centres. Information about TB varied across community settings and did not seem to help participants identify the disease, which suggests a need for more innovative TB education. Thus, the findings from this study highlight the multitude of ways in which community setting can impact the high rates and advanced

presentations of TB among Indigenous Peoples in the Prairie Provinces, pointing to clear implications for improving policy and practice and the need for greater investment in public health.

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