Respiratory isolation for tuberculosis: the experience of Indigenous peoples on the Canadian prairies

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Setting: The Prairie provinces of Canada.

Objective: To understand how Indigenous peoples with infectious pulmonary tuberculosis living in different community settings in the Prairie provinces of Canada experience respiratory isolation.

Design: Using an exploratory qualitative approach, we interviewed participants living in urban centres, non-remote reserve settings and remote and isolated reserve settings.

Results: Through qualitative content analysis of 48 interviews, we determined that participants experienced feelings of confinement regardless of the community setting in which they lived. Participants also experienced family and social disconnect, but the experience was more potent for the remote and isolated reserve participants, who were required to be flown out of their home communities to receive treatment, and for those urban centre and non-remote reserve participants who lacked social connections. The roles of past experiences with sanatoria and of family in providing social support are discussed.

Conclusions: The conclusions of this study focus on examining isolation policies and improving the hospital isolation experience.

In Canada, the Prairie provinces have consistently reported higher tuberculosis (TB) rates than the national average (4.8 per 100 000 population in 2012; absolute number of cases 1685), with Alberta, Saskatchewan, and Manitoba at respectively 5.1, 8.4, and 10.8/100 000 (with the absolute number of cases respectively 196, 91 and 137).¹ Indigenous peoples* and their communities continue to be disproportionately reflected in these high TB rates,³ comprising over 50% of the Canadian-born TB cases in the country.^{4–6} Indigenous peoples living in the Prairie provinces have the most advanced presentations of TB disease.³ Although Canadian standards regarding TB management procedures do exist, these standards are enacted differently through guidelines at the provincial/territorial level. For example, there are both federal and provincial/territorial requirements to isolate patients

at the initiation of treatment for infectious TB; however, provinces/territories have different requirements as to where individuals with TB must be isolated.

Studies have found that patients who are isolated for extended periods of time, regardless of disease, experience greater levels of anxiety, depression, anger and feelings of imprisonment,^{7–11} which is difficult for patients and their families.¹² Research to date has not considered how isolation impacts Indigenous peoples. This is important given the unique historical experiences of Indigenous peoples undergoing anti-tuberculosis treatment in the early 1900s. Near the turn of the twentieth century, sanatoria were established to segregate infectious patients from the rest of society and promote healing, first of non-Indigenous and later Indigenous patients, by offering a nutritional diet, rest, fresh air, and sunlight.¹³ Although eventually every individual with suspicion of TB was required to be treated in a sanatorium, the implications for Indigenous peoples, who often only spoke their first language and were far removed from their communities, have been particularly significant (i.e., lost family members, cultural disconnect).¹⁴ Today, sanatoria no longer exist, and policies on how to treat TB have changed, yet in the management of infectious TB, isolation, whether at home or in hospital, is still recommended. Typically, individuals with infectious TB are isolated at the outset of treatment, as per management policies that differ across the Prairie provinces of Canada.

TREATMENT POLICIES ACROSS THE PRAIRIE PROVINCES

The Government of Alberta's Tuberculosis Prevention and Control Guidelines¹⁵ and the Manitoba Tuberculosis Policy¹⁶ maintain clear legislation for cases with suspected TB: all individuals who have pulmonary TB must remain in isolation until they are proven to be non-infectious. In Alberta, home isolation is permitted; however, this option has historically not been offered to Indigenous patients residing in reserve communities with infectious pulmonary TB. Mobility and a communal living habit have been judged to confound the ability to provide home isolation.¹⁵ Manitoba does not provide the option of home isolation. Under the Public Health Act, if individuals refuse or neglect to comply with conditions of anti-tuberculosis treatment, they may be apprehended and detained.^{15,16}

In the province of Saskatchewan, a more patient-centred approach to treatment is preferred, whereby

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KEY WORDS

Indigenous peoples;
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* Indigenous peoples are often treated as a homogeneous group, which is a large misconception. Each Indigenous community has its own culture, traditions, language and specific history.² In addition, each Indigenous community and reserve has varied access to education, health and social services, housing, roads and basic infrastructure. For the purpose of this study, we use the term Indigenous peoples (plural) to acknowledge the rich diversity among Indigenous peoples of Canada.

treatment is typically given in the patient's home with support from a community-based team. Such an approach assumes that patients at low risk of drug resistance are rapidly rendered non-infectious after the introduction of effective directly observed treatment. If patients are particularly ill, they may require specialised TB treatment in a hospital setting, albeit for a limited number of days, before returning to their home to complete treatment. Visitors are allowed in the home if the patient wears a face mask, but family members may be required to leave the home for a period of time if they are at a high risk of progressing to disease if infected (i.e., young children, individuals who are immunocompromised). Saskatchewan uniquely provides mobile clinic care. Both Alberta and Saskatchewan also provide TeleHealth (videoconferencing) services to patients living outside urban centres, reducing the need to travel to urban centres for follow-up appointments.^{17,18} In all provinces, patients are informed of the rationale for respiratory isolation.

The services/benefits available to Indigenous and non-Indigenous patients in respiratory isolation are similar across the prairies. Most isolation rooms that meet environmental engineering controls are in tertiary or quaternary care hospitals. Many rooms have an en suite bathroom, and some are equipped with a television and internet access. Telephone communication is possible. Full consultation and investigational capacity is usually available, although an attempt is made to limit the number of off-ward investigations, for reasons of infection control and occupational health and safety. A range of paramedical services, including social work, occupational and physical therapy, dietetics, and translational and pastoral services, is usually available. Volunteers are usually available to provide library services and arts and crafts opportunities. Regular visiting hours are scheduled, and families are permitted to supplement hospital food with home cooking. The ability to go outdoors is often limited, especially if, as in some programmes, the patient must be accompanied by a staff member.

Generally, patients are hospitalised as close to home as possible, capacity—including human resources—permitting. Services unique to Indigenous peoples include an on-call Aboriginal Liaison Worker, who has the ability to perform ceremonies, and, for patients coming from reserve communities, especially those who are medically unstable or require prolonged hospitalisation, community support of family member visits to the patient. Upon discharge, transportation back to reserve communities is funded.

Despite some variation in isolation policies, as well as advances in treatment, TB rates across all three Prairie provinces have shown little improvement in the last decade, and in some years rates have actually increased.

Community setting

Indigenous peoples live in various community settings, including urban centres, non-remote reserves,³ remote reserves and isolated reserves. Statistics Canada defines an urban centre as a non-reserve community with a population of between 1000 and 100 000.¹⁹ Health Canada defines a non-remote reserve as being located within 350 km from an urban centre.²⁰ A remote reserve community is a 'geographical area where a First Nations community is located over 350 km from the nearest service centre having year-round road access'. An isolated reserve community is a 'geographical area that has scheduled flights and good telephone services; however it is without year-round road access'.

Every community setting is unique in its history, cultural identity, population, resources and health services. Kaspar notes that community is one of the most under-addressed ecological influ-

FIGURE Map of Canada highlighting the three Prairie provinces: Alberta, Saskatchewan and Manitoba. The five red dots indicate the location of the major metropolitan areas on the prairies. NL = Newfoundland; PEI = Prince Edward Island; NB = New Brunswick.

ences that affect health determinants for Indigenous peoples.²¹ Interestingly, while TB has devastated some Indigenous communities, others remain comparatively untouched.²² Given these circumstances, the objective of the current study was to understand how Indigenous peoples living in different community settings in the Prairie provinces experience respiratory isolation treatment for TB.

STUDY POPULATION, DESIGN AND METHODS

This study is part of a larger research project, entitled The Determinants of Tuberculosis Transmission among the Canadian-born Population of the Prairie provinces (DTT project).²³ The 7-year DTT project (1 April 1 2006–31 March 2013) was an interdisciplinary study aimed at understanding the environmental, biomedical, socio-cultural and historical determinants of TB transmission in Indigenous peoples from Alberta, Manitoba and Saskatchewan, the Prairie provinces (see Figure). The research team was made up of social scientists, Indigenous health researchers, clinicians and epidemiologists. An Indigenous consultative team based at the University of Alberta developed the project.²³ Provincial network committees, consisting of over 50% Indigenous peoples, were established in each province and included health professionals, elders, traditional healers, Indigenous and government stakeholders and former TB patients. These committees guided all aspects of the research.

DTT participant recruitment

DTT project participants were accessed through medical professionals (i.e., doctors and nurses) across Alberta, Saskatchewan and Manitoba. To be eligible for participation in the DTT project, participants had to be aged ≥ 15 years, Canadian-born and diagnosed with culture-positive pulmonary TB in one of the Prairie provinces

between 2007 and 2008. The participants were first invited to complete a questionnaire that asked demographic questions (i.e., age, sex, occupation, educational attainment) and questions about their TB (i.e., prior infections, symptoms, where they received their diagnosis). Participants who completed a questionnaire and were sputum smear-positive by fluorochrome stain, confirmed by carbol fuchsin staining or reading by another qualified individual, were further invited to participate in an interview ($n = 112$). A positive smear means that there are numerous bacteria in their sputum (estimated at 5000–10000 bacteria/ml of sputum), and although their infectiousness can vary, smear-positive patients are, as a group, considered to be the most infectious TB patients.

Data collection and analysis

An exploratory qualitative approach was used to understand the TB treatment experiences of Indigenous peoples living in different community settings across the Prairie provinces. Interview questions were broad to enable participants to describe their TB experience organically, with occasional prompting from the interviewer. Participants were asked questions about their current experience and perceptions of TB, their life history as it relates to the social determinants of health and their general ideas about being healthy.

A DTT project interviewer (i.e., a TB nurse, an Indigenous educator or a health researcher) reviewed the study information sheet and consent form with those participants who were interested in being interviewed. Participants aged <18 years living with a parent or guardian required parental consent.

Interviews were recorded and transcribed verbatim, and were analysed using qualitative content analysis²⁴ by five research team members (three interviewers and two academics) living across the Prairie provinces. The transcripts were first read in their entirety to develop an understanding of the content, and were subsequently re-read and reviewed line by line, with codes generated to highlight important ideas and concepts. Data collection and analysis were performed concurrently; after three to four interviews had been conducted in each province, the interviewer for that province and one academic would analyse the data, share the analysis with the rest of the team and then conduct more interviews based on emerging analyses. The use of Atlas.ti 5.2 (Scientific Software Development GmbH, Berlin, Germany) made it easy to share analyses electronically across the provinces. In addition, the team met in person twice during data collection to analyse the data by community setting and within and across provinces. Data collection ceased when interviews with 56 smear-positive participants were complete and data saturation was reached. The team agreed there was repetition in the data, all leads had been followed and negative cases had been checked, and decided additional interviews would not add anything new to the analysis.

It was clear early in the analysis that the isolation experience was identified as critical to the overall experience of TB, and that community setting played a role in this experience. Near the end of the analysis, because the isolation experience was very similar for those participants living in remote and isolated reserve settings, the participants' data for these two settings were combined. Similar codes related to respiratory TB isolation treatment were grouped into categories and were reworked until descriptions of these categories were succinct, and evaluated to be internally and externally homogeneous.²⁴

The Table outlines the participant characteristics. Participants were men and women, aged 17–62 years and from various community settings (where participants lived at the time of their diag-

TABLE Participant characteristics

Province	Community setting*	Sex	Age, years, mean
Alberta	Urban centre ($n = 7$)	Male ($n = 8$)	40.5
	Non-remote reserve ($n = 7$)	Female ($n = 6$)	
	Remote/isolated reserve ($n = 0$)		
Saskatchewan	Urban centre ($n = 6$)	Male ($n = 6$)	36.0
	Non-remote reserve ($n = 4$)	Female ($n = 10$)	
	Remote/isolated reserve ($n = 6$)		
Manitoba	Urban centre ($n = 8$)	Male ($n = 8$)	41.1
	Non-remote reserve ($n = 4$)	Female ($n = 10$)	
	Remote/isolated reserve ($n = 6$)		

* See text for definition of community settings.

nosis), providing a wide range of perspectives on the experience of Indigenous peoples living with TB. Of the 56 interviews, 48 were used for this analysis. Eight interviews were not included because they were from a unique urban community setting with a population of approximately 95% Indigenous peoples and significantly high TB rates. Participants from this setting had a very different experience, requiring a separate analysis.

RESULTS

The findings illustrate the impact of respiratory isolation on participants' wellbeing during TB treatment. As a result of being isolated in hospital for varying periods of time, participants across all community settings shared feelings of being 'sad', 'really, really bored', 'alone', 'trapped', 'lonely', 'frustrated', 'like they were in jail' and 'isolated'.

Participants' experiences can be described through two categories: 1) confinement and 2) family and social disconnect. All participants who were isolated in hospital, regardless of province or community setting, described experiences that corresponded to their category of confinement. In contrast, with respect to the category of family and social disconnect, the TB hospital isolation experience differed for two groups, namely for the remote and isolated reserve participants who were required to be flown out of their home communities to receive treatment, and for those urban and non-remote reserve participants who lacked social connections.

Confinement

Participants who were isolated in hospital described feeling annoyed at not being 'allowed to go anywhere else' or to 'walk around', and indicated that it was difficult to be 'in bed and inside the room'. Participants were accustomed to leading independent lives and expressed frustration over being 'trapped' in the same room for extended periods of time. One participant noted: 'it was stressful for me. I have a history of anxiety and it was difficult to be isolated, with the door shut all the time'. Another participant explained that it '[wouldn't] be so bad if you could go outside'. This desire to go outside was shared by many participants. One in particular stated: 'I'm more of an outdoors person and they're keeping me indoors. It's so boring...I'm not allowed to go outside...Just lay on the bed and watch TV. ...I miss home a lot. It's boring here'.

With little to do, participants described simply trying to get through their day. As one participant described, '[i]t was pretty hard I guess 'cause you just stay there and watch TV and just think too much. All you have to do is just get another pill or to just fall asleep'. A Saskatchewan participant, isolated in a hospital for a brief period of time before being sent home, stated:

Even at the hospital when people come around me they had masks and stuff on and I felt bad...they left me in a room by myself and the doors closed. My mom came but she didn't stay long because those masks...she couldn't really breathe. (Saskatchewan, Urban Centre)

Time in the hospital was compared to being in jail, and participants made comments such as, 'I'm sick and tired of it...It's, well, just to be in jail. I'm not allowed to go anywhere else'. A grandmother felt as if she was being arrested upon diagnosis, and the feeling of imprisonment continued throughout her treatment:

The way I feel right now, well when I first got dragged over here, I'll say because that's how I felt right from the moment the nurse told me to pack up my stuff, just like that you know. She made me feel like a prisoner, that I was under police custody. (Manitoba, Isolated Reserve)

The confinement felt by participants led them to want to 'walk out' or 'get out':

I don't like staying in one room; I don't like looking outside 'cause it's too depressing. You see people walking around and doing things. Mostly I try not to think about it. If I thought about it I'd probably try to walk out. (Alberta, Non-Remote Reserve)

Another participant had warned his doctor: '[I] told my doctor "I wanna get out of here. Give me a chance to see a way out. I'll sneak out of here".' These feelings of being trapped were common, and inevitably led some participants to leave the hospital against medical advice. As one participant stated, '[s]ometimes I feel like going home because I've never been out and never been this long outside of my house, my home. Just feel like going home sometimes.' She later did just that, and it took staff 2 days to find her. Another participant, tired of being in her room all day, explained:

I was crying because my doctor phoned me, said I better go to the hospital. 'There's a bed for you now'. So I got mad at everything and then my doctor says 'you have to go because if you don't go, sometimes you die on it' and that they're picking me up right away and then I'm over there just like in jail with locks...[After] two weeks I sneaked out...I came back home. (Manitoba, Urban Centre)

One woman from Saskatchewan had been transported to a small urban centre to receive treatment and stated: 'I didn't feel like staying in the hospital. I was mad...I was supposed to stay there a month but I walked out.' Her doctors decided that she would not return to the hospital and that the best they could do would be to continue her isolation treatment at home. All participants who were isolated in hospital, regardless of province or community setting, shared experiences of feeling confined, trapped or jailed.

Family and social disconnect

Upon entering hospital isolation, participants described experiencing a great deal of sadness and disconnect over being separated from their family members. They acknowledged that their friends and family were often fearful of visiting because of the di-

agnosis of TB and the isolation setting. One participant described how her sister, who was the only family member in her life, drove her to the hospital, but had not returned, as she was 'too scared'. Being isolated in hospital caused many participants to feel as though people no longer wished to be around them, 'like nobody don't want you no more. You got a sickness and you can stay there until that sickness goes away. If it doesn't go away you're by yourself there'.

Participants who were mothers noted that it was especially difficult to be separated from their children. Most often, children, who were being pre-emptively treated for TB infections, lived far away, and/or were too young to visit their parent in isolation. A mother described leaving her husband and eight children behind:

They don't listen to their dad as much, that's why when I'm here my husband phones me and tells me to tell them to do this, do that, because they don't listen to him and they listen to me more. (Manitoba, Urban Centre)

Participants who were isolated often had to rely on family members to care for their children. A young mother had been transported 4 hours north to a large urban centre in Alberta for treatment, and expressed guilt over relying on her parents to take care of her children and the possibility that she had passed her TB on to them:

They've already done so much in taking care of the kids. Taking time out of their lives to watch my kids... I just felt guilt. I was gonna be away from my kids for that long...I'm just worried about my kids getting sick too. (Alberta, Non-Remote Reserve)

Masks must be worn by those who visit patients in isolation. Because available masks do not fit young children properly, and very young children are at increased risk of progressing, not only to disease, but to severe forms of disease if infected, the minimum age to visit patients in isolation is 12 years. A mother shared that her youngest child had called and yelled at her to 'come home now'. She explained that it was difficult knowing her children were having a challenging time, that she 'cried' and 'wished to go home'.

Feelings of disconnect were exacerbated for mothers from remote and isolated reserves, as they were required to be flown out of their communities for treatment. After receiving a TB diagnosis, one mother stated that she was 'disappointed' and 'felt alone' because she knew she would be getting 'medevaced out'. Another mother was required to leave her newborn baby behind, preventing her from continuing to breast feed. Another mother described having a difficult time explaining to her children that they would not be able to visit her because she was too far away. Another mother shared that:

On Monday night I told my kids. Well my 6-year-old daughter understood and I told her I'd be going away to the doctor and I'm gonna stay there until I got better and she cried all evening, so I talk to her every day. Her first question is always 'are you getting better?' (Manitoba, Isolated Reserve)

Participants from urban centres without strong social connections described unique and often intensified isolation experiences. For these participants, even if friends (including those who lived in boarding houses, on the street and/or in shelters) or family could visit, no one did. One participant communicated that she was 'lonely' because she 'had hardly any visitors'. The lack of visitors was often attributed to patients' friends not knowing where they were or to their inability to contact them as 'they don't know

about me being sick. I haven't seen them yet. I haven't seen those guys since I came in'. Another participant explained that he 'hadn't been able to use the phone yet' and 'had not been able to speak to anyone since entering the hospital'. One participant who was transferred from a small urban centre to a larger one for treatment stated '[t]he only thing is, I can't talk to nobody because I don't know nobody around here'. Acknowledging the difficulty of not having visitors, one participant stated that '[i]t's harder. Some of them [other patients] give up right away. They don't even, like they're deserted so they just give up and die'.

DISCUSSION

Regardless of community setting, participants described feelings of confinement and disconnect while being isolated in hospital to receive treatment for TB. These findings can be understood through Indigenous peoples' sanatoria experience and the role of family in their lives, and have profound implications for reconsidering TB isolation policy, hospital isolation practices and preventing overall TB transmission among Indigenous peoples.

Sanatoria

Participants' stark descriptions of confinement and family disconnect mirror the historical treatment of TB in sanatoria. The results of the sanatoria experience for Indigenous peoples include fear of being arrested when symptoms of illness were present^{25,26} and painful and scarring memories of lost family members. Public health officials often employed coercive tactics (i.e., withholding funding to reserves until the community members submitted to an X-ray) to force Indigenous peoples to know their TB status and, if determined to have disease, be admitted to the nearest sanatorium.^{25,26} Non-Indigenous staff members generally lacked the capacity and language to explain TB and the treatment process to Indigenous patients, which perpetuated confusion and fear.^{25,27} Former sanatoria patients have described their inability to practise traditional healing methods as contributing to feelings of loss and cultural disconnect.²⁵ Indigenous patients often died in sanatoria without their families being notified.^{20,28,29} Because of poor patient records, those who survived treatment were often unable to return home, as they did not know where they were or how to get back to their families.²⁸

Given this history of TB treatment and the associated negative experiences for Indigenous peoples,²⁶ it is not surprising that hospital isolation is experienced as being similar to jail, with deep fears about returning home or never seeing family members again. This is also informative in explaining why many Indigenous peoples may present to health care providers with such advanced disease.^{30,31} It may also deter patients from sharing information about their contacts (family members/friends), where identification and assessment is necessary to prevent the spread of the disease. Given the disproportionate number of Indigenous people in correctional facilities in Canada,³² the parallel drawn between the isolation experience and incarceration is also particularly significant in understanding how isolation treatment may impact Indigenous patients' early disclosure of symptoms.

Role of family in providing social support

Family involvement is critical during a patient's health care journey,³³ particularly for Indigenous peoples who traditionally place significant value on kinship networks.³⁴ Research has drawn strong linkages between social support and physical health,³⁵ as well as between patients' access to family members and their levels of comfort and wellbeing during the process of physical healing.³⁶

On the contrary, enduring lengthy treatment for health issues alone or with limited access to friends and family can result in negative impacts on patients and their loved ones.^{12,37,38} Participants, and in particular mothers, described disconnection from family as being an incredibly difficult experience, and even more so for those participants from remote and isolated reserves who had to be flown out of their communities. For urban participants, disconnection was described even more potently, as they did not have visitors throughout the time they received treatment. These findings are in agreement with research on experiences of disruption and loss by Indigenous women removed from their home communities to give birth.³⁷ These mothers described feeling extreme sadness and grief over their separation, and worried about the wellbeing of the children they left behind. In our study, mothers expressed guilt over placing an extra burden on family members to provide child care. Participants in other studies of TB experiences have echoed these feelings of guilt.^{39,40}

In addition to established values related to living collectively with strong kinship relationships, it is well known that Indigenous peoples traditionally have a strong attachment to the land.^{41,42} Indigenous peoples are highly mobile and move between communities and provinces.^{41,42} Accordingly, the experiences of hospital isolation for TB treatment may be particularly difficult to endure for many Indigenous peoples.

Recommendations

Examining isolation policies

Isolation policies that require hospitalisation significantly impact the lives of individuals with TB and their relationships, and can evoke past trauma related to sanatoria. With an appreciation for the complexity of isolation policies and practices, hospital vs. home isolation should be examined in the context of TB rates and other relevant evidence. The Canadian Tuberculosis Standards¹ recommend isolation at the outset of treatment for infectious TB, although most Indigenous communities do not have isolation capacity in their health centres. This renders isolation outside of home communities inevitable, which can be particularly distressing for Indigenous patients from remote and isolated reserves. Adding to the negative experience of hospital isolation is the fact that patients confined to respiratory isolation rooms in acute care hospitals may not be able to go outside unless accompanied by staff. The irony is that in most sanatoria of the past patients were allowed to walk and visit on what were often beautiful grounds surrounding the facility; contemporary isolation and past segregation policies differ.

Importantly, Saskatchewan's treatment policy allows participants to be isolated at home. While young children, babies and individuals with weak immune systems may be required to leave the home during isolation treatment, visitors are permitted and patients can spend time outdoors. In turn, Saskatchewan participants in this study isolated at home did not compare their time in treatment to jail. However, the TB rates in Saskatchewan remain relatively high in comparison to the Canadian average. At the same time, Manitoba requires isolation to occur in a hospital setting, and the TB rate is even higher than in Saskatchewan, calling into question the link between isolation and TB rates. Although Alberta appears to be making the largest strides in the fight against TB in Indigenous peoples, Alberta participants in this study described highly negative feelings while in hospital. When patients return home, it is possible that they may share these negative experiences with their family, friends and community, which could impact their desire to be tested for TB and en-

able the illness to be spread. Furthermore, as there is increasing evidence that pulmonary TB patients are rendered non-infectious quite rapidly once they are placed on effective treatment,⁴³ current isolation policies should be considered in light of this evidence. Regardless of isolation policy, there remains a persistent need across the provinces for greater education about TB and the rationale behind its management, not just for individual patients but also for high-incidence communities as a whole.

Improving hospital isolation

Health services should, when possible, allow increasing involvement from family members to provide TB patients with a more positive and stimulating hospital experience. Individuals with family involvement may be more willing to enter the hospital sooner (prior to the infection worsening), their stays may be shorter, and they may not spread their infections to as many people. Furthermore, including more individuals in the TB treatment process could increase patient support to continue their medication upon returning home, reducing the need for longer or protracted courses of treatment due to treatment non-adherence.

In addition, more work is required to support patients who do not have 'typical' family and social connections, such as urban participants in the current study. Creating more stimulating hospital environments could ultimately improve the experiences of individuals who lack visitors by creating opportunities to build relationships with others in the hospital. For example, many hospitals provide patients with various activities (e.g., art and pet therapy) to combat feelings of boredom and depression.⁴⁴ It has also been noted that TB clubs can improve social and emotional wellbeing and reduce feelings of stigma and shame.⁴⁵ Finally, a system should be in place to allow patients to go outside from time to time.

Limitations

Tuberculosis is clearly a complex health issue. This study aimed to understand respiratory isolation and transmission more broadly, and therefore did not fully capture some of the issues that contribute to high TB rates within some communities, such as the historical experiences that continue to affect perceptions of TB. Furthermore, the current study did not address many related issues, such as crowded housing, poverty and other chronic health conditions. Interviews were conducted very soon after treatment initiation, and participants had not returned home to continue treatment—with the exception of most of the Saskatchewan participants. The impact of having to cross jurisdictional lines (i.e., on-reserve, off-reserve) to be treated for TB was therefore not fully explored, although this is another significant policy consideration. This impact will be important to explore in future research, as a lack of seamless transition between provincial (non-reserve) and federally (reserve) funded services can have negative impacts on Indigenous peoples.⁴⁶ Another possible limitation is the timing of the interviews. Because we interviewed participants very soon after hospitalisation and treatment initiation, their full experience was not captured. However, we believe this actually makes the findings with respect to respiratory isolation more persuasive, as it is expected that their feelings of confinement and family disconnect would only worsen over time.

Finally, the sample of remote and isolated participants in this study was much smaller than the sample of urban and non-remote reserve participants. Likewise, the sample of on-reserve patients in Saskatchewan, where a home isolation policy is favoured, interviewed outside of hospital and in the community was not large, precluding a meaningful comparison with on-reserve patients in Alberta and Manitoba, where a hospitalisation policy is favoured.

Future qualitative research would benefit from a larger group of participants from these community and provincial settings to provide a deeper understanding of their diverse experiences with TB.

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Contexte : Les provinces de la Prairie au Canada.

Objectif : Comprendre comment les populations indigènes atteintes de tuberculose pulmonaire contagieuse, vivant dans différents contextes communautaires dans les provinces de la Prairie au Canada, ressentent l'isolement.

Schéma : En utilisant une approche exploratoire qualitative, nous nous sommes entretenus avec les participants vivant dans des centres urbains, ou dans des réserves éloignées non isolées et dans des réserves éloignées et isolées.

Résultat : Une analyse qualitative du contenu des 48 entretiens nous a permis de déterminer que les participants ont eu des sentiments de

confinement quel que soit le contexte communautaire dans lequel ils vivaient. Les participants ont également vécu une coupure familiale et sociale, mais l'expérience a été plus dure pour les participants des réserves éloignées et isolées qui ont été obligés de quitter leurs communautés pour recevoir leur traitement, et pour les patients des centres urbains et des réserves non éloignées qui manquaient de connections sociales. Le rôle des expériences passées avec les services de santé et avec le soutien social de la famille est discuté.

Conclusions : Les conclusions se concentrent sur l'examen des politiques d'isolement et l'amélioration des expériences d'isolement à l'hôpital.

Marco de referencia: Las provincias de las Praderas del Canadá.

Objetivo: Comprender de qué manera perciben el aislamiento respiratorio las poblaciones indígenas con tuberculosis pulmonar contagiosa, de diferentes entornos comunitarios en las provincias de las Praderas canadienses.

Método: Mediante una estrategia exploratoria cualitativa, se entrevistaron los participantes que residían en centros urbanos, en reservas no distantes y en reservas aisladas y distantes.

Resultados: Tras el análisis cualitativo de contenido de 48 entrevistas, se determinó que los participantes percibían una sensación de confinamiento, con independencia en su entorno comunitario.

Asimismo, los participantes percibían desconexión familiar y social, pero la experiencia fue más intensa en los participantes de ámbitos distantes y aislados que tenían que salir de sus comunidades por vía aérea con el fin de recibir el tratamiento y en los participantes de centros urbanos y reservas no distantes que carecían de conexiones sociales. En el artículo se analiza la influencia de las experiencias pasadas con sanatorios y la función de la familia en la prestación del apoyo social.

Conclusión: Las conclusiones se centran en el análisis de las políticas de aislamiento y las iniciativas de mejoramiento de la experiencia hospitalaria del aislamiento respiratorio.