

“Finally when I started falling down”: Indigenous Tuberculosis Patient Experiences of Health and Illness on the Canadian Prairies

Abstract

This paper adds evidence to a growing body of literature seeking to understand the disproportionate occurrence of tuberculosis (TB) in Indigenous populations of Canada and reveals insights that may inform effective interventions. As a disease, TB is recognized as a disorder of the body, for which there are successful treatments. Its persistence in some populations, however, requires an understanding of TB as an illness, whereby disease is shaped into behaviours and experiences. Fifty-five self-identified Indigenous participants with infectious pulmonary TB completed a questionnaire and an interview as part of the Determinants of Tuberculosis Transmission (DTT) project. Questionnaire data report on sociodemographic information and exposure to TB risk factors, while interview data describe participants’ experiences of TB within the context of their personal histories and everyday lives. Analysis showed that TB symptoms did not stand out as unusual in the everyday life and health experiences of participants. State of health and decisions about accessing healthcare were associated with socioeconomic deprivation, as well as negative experiences connected with historical and contemporary impacts of colonization. The “tipping point” concept effectively captures the shift in health that pushes participants to seek healthcare. Family, friends, and other caregivers are important influences and need to be part of the effort to avoid advanced TB illness and stop the cycle of transmission. More significantly, there is a need to address the structures and systems that produce and perpetuate life conditions that result in a usual state of compromised health.

Keywords

Tuberculosis, Indigenous, Canada, social determinants of health, illness experience, tipping point

Note on Terminology

We use the term *Indigenous* throughout this paper to refer to the first inhabitants of what is now called Canada. In a global context, this term links peoples in similar circumstances of colonization. Where it appears in the text, the term *Aboriginal* refers to a formal recognition of Indigenous people in Canada in the Constitution Act of 1982, as members of three groups: First Nations (“Indians”), Métis, and Inuit. Terms used throughout this paper reflect those used in source material. Where we report epidemiological information from our research, we use terms consistent with federal government reporting standards for comparability.

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Introduction

Tuberculosis (TB) disease variably affects persons worldwide, with Canada having a low national incidence (Public Health Agency of Canada, 2015). TB can affect any organ of the body, though it primarily targets the lungs. Through cough, the bacterium can be transmitted through a process of aerosolization. Disease can occur either imminently or many years after the initial infection. When an infectious state of disease occurs prior to diagnosis, affected individuals may be implicated in increased transmission.

In the Canadian Prairie provinces, TB variously affects Aboriginal people, with incidence rates per 100,000 in 2013 that ranged from 51.1 in Manitoba to 33.1 in Saskatchewan and 6.3 in Alberta. This contrasts with a national incidence of 4.7 in the same year (Public Health Agency of Canada, 2015). Aboriginal people accounted for 90% of Canadian-born adult culture-positive (for *Mycobacterium tuberculosis*) pulmonary TB cases on the Prairies (Long et al., 2013). Sixty-one percent of these cases were not just culture-positive but also smear-positive, indicating a high degree of infectiousness. Epidemiological analysis has further revealed that, outside of Winnipeg, Manitoba, most cases of pulmonary TB among First Nations and Métis people on the Prairies occurred in a relatively small number of communities north of the 53rd parallel (Long et al., 2013). The inequitable persistence of TB, despite the availability of effective medication, is unacceptable and points to a need for understanding and addressing the drivers that enable TB to persist in Indigenous communities.

This paper draws on data collected in association with the Determinants of Tuberculosis Transmission (DTT) project, an interdisciplinary, multiple-method study grounded in a population-health orientation that began in April 2006. A major objective of the DTT project is to understand the social determinants of TB transmission among the Canadian-born adult population of Alberta, Saskatchewan, and Manitoba with the goal of contributing to the interruption of TB transmission via evidence-informed interventions. A more detailed discussion of the overall DTT project objectives and methodology has been previously published (Boffa, King, McMullin, & Long, 2011). The stories of individuals whose disease progressed to the point of potential infectiousness can reveal important insights about the circumstances that lead to moderate to advanced TB disease and, ultimately, to increased transmission.

Illness and Historical Context

TB Disease Persistence in the Experience of Health and Illness

This paper adds evidence to a growing body of literature that seeks to understand the disproportionate persistence of TB disease in Indigenous populations of the Canadian Prairies and uncover insights that may inform effective interventions. As a disease, TB may be understood as a specific disorder of the body, for which there are effective treatments. Its persistence in some population groups, however, requires an understanding of TB as an illness, which Kleinman (1981) describes as the shaping of disease into behaviours and experiences

through personal, social, and cultural reactions to disease. We also drew on Mechanic’s (1982) elaboration of illness behaviour as the way people monitor their bodies (or others’ bodies), define and interpret their symptoms, act, and access care. The basic concepts of illness advanced in these early works hold currency for contemporary TB research (Mason, Degeling, & Denholm, 2015). They lend themselves well to a contemporary population-health orientation that demands attention to the social determinants of health, in considering how disease is shaped into persistent illness through actions and reactions that include, but also move beyond, the personal, social, and cultural to include the political and structural (Møller, 2005, 2010).

Colonization Context

The negative health and social consequences of a long history of colonization, with increasingly aggressive assimilation policies from the end of the 19th century forward, have been extensively described (e.g., Greenwood, de Leeuw, Lindsay, & Reading, 2015; Royal Commission on Aboriginal Peoples, 1996; Waldram, Herring, & Young, 2006). Of significance in this research is residential school policy and mid-20th-century TB treatment in which sanatorium placement was a predominant feature.

While they were established in the 1880s, beginning in 1920 it became mandatory for all First Nations children in Canada aged 7–15 to attend residential schools, where the goal was to assimilate these children into the broader Canadian society (Milloy, 1999). Widespread reports of physical and sexual abuse, poor health with TB identified as an urgent and prevalent issue, and malnutrition have emerged from this era (Bryce, 1922; Milloy, 1999; Mosby, 2013). The last government-run school did not close until 1996. Similarly, from the 1940s to 1960s Aboriginal TB patients were apprehended from their communities to TB sanatoria at some distance from their homes, sometimes for years (Moffatt, Mayan, & Long, 2013). While we touch on its relevance in our Results and Discussion, we have detailed the importance of the sanatorium history for participants in our study elsewhere (Komarnisky, Hackett, Abonyi, Heffernan, & Long, 2016). The disruption to families, communities, and cultures was profound, with the impact of schools recently documented in the summary report of a 5-year national Truth and Reconciliation Commission (Truth and Reconciliation Commission, 2015). Colonization effects, particularly effects of residential schools, are included among the social determinants of health in the population health framework of the Assembly of First Nations that informed this study (AFN, 2006).

Relationships

The DTT project is a patient-based study that followed an extensive engagement and ethical approval process with multiple jurisdictions including Indigenous and non-Indigenous stakeholders. In anticipation of a large number of diagnosed patients in the study period identifying as Indigenous, we followed the Canadian Institutes of Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal Peoples*, which were the only national

ethical guidelines in place at the time this study began and which reference the OCAP principles (ownership, control, access, possession)¹ as foundational to the development of research agreements with Aboriginal communities (CIHR, 2013; NAHO, 2005). As a patient-based rather than community-based study, the project was overseen through ongoing consultations with Provincial Network Committees (PNCs), one in each participating province, that were established to guide the study. The PNCs comprised Indigenous Elders, traditional healers, healthcare workers, former patients, and representatives from Aboriginal and governmental stakeholder groups. The process of establishing these committees and acquiring the administrative and ethical approvals is described in detail elsewhere (Boffa et al., 2011). Institutional-level ethics approvals were received from Health Canada and the Prairie province Universities of Alberta, Calgary, Saskatchewan, and Manitoba. In addition to making community visits, a research coordinator in each province participated in local radio interviews to raise awareness of the study.

Methods

Healthcare Context

Potential participants for this study were recruited shortly after their TB diagnosis and as they were navigating treatment and care, which varied according to province of residence and community of residence. In Canada, each province and territory has its own TB prevention and care program, and although they all rely upon the best practices outlined in the Canadian TB Standards (Public Health Agency of Canada & The Lung Association, 2007), they all differ somewhat in how these practices are implemented. For First Nations patients, ancillary services are provided to reserve communities by First Nations Inuit Health either directly or indirectly (e.g., through transferred organizations such as the Northern Intertribal Health Authority in Saskatchewan). Across community types (reserve communities; Métis settlements, or Northern Villages as they are called in Saskatchewan; major metropolitan areas; and non-major metropolitan areas), a wide range of service delivery models were in place at the time of this study. Within Indigenous communities, healthcare provision capacity varied, often based on community size and relative remoteness—from some having a hospital, 24/7 physician coverage, and X-ray facilities, to others having a health centre with a nurse in charge only some of the time and no X-ray facilities.

Participants and Data Collection

All adult (> 14 years), Canadian-born, culture-positive pulmonary TB patients diagnosed in a Prairie province between January 1, 2007, and December 31, 2008, and whose contacts were

¹ OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC; www.fnigc.ca).

followed until December 31, 2010, were eligible for inclusion in the overall DTT study ($N = 248$; 223 Indigenous). Out of those eligible, 183 did and 65 did not participate in an oral questionnaire. Of those that did not participate in the questionnaire, 56 were Indigenous (30 were never invited to see a research coordinator about the project, 17 died, and 9 declined). Questionnaire participants who were sputum-smear-positive at diagnosis, indicating a high degree of infectiousness ($n = 112$; 101 Indigenous), were invited in successive order to participate in an in-depth interview until data saturation was reached. The same research coordinator conducted both the questionnaire and the interview with participants in their respective provinces. Quantitative and qualitative data for each participant were coded with the same case-specific anonymized unique identifier allowing for data linkage. Interviews were conducted with 55 self-identified Indigenous TB patients: 18 in Manitoba, 24 in Saskatchewan, and 13 in Alberta. Figure 1 provides a summary of the eligible population and participants in this study.

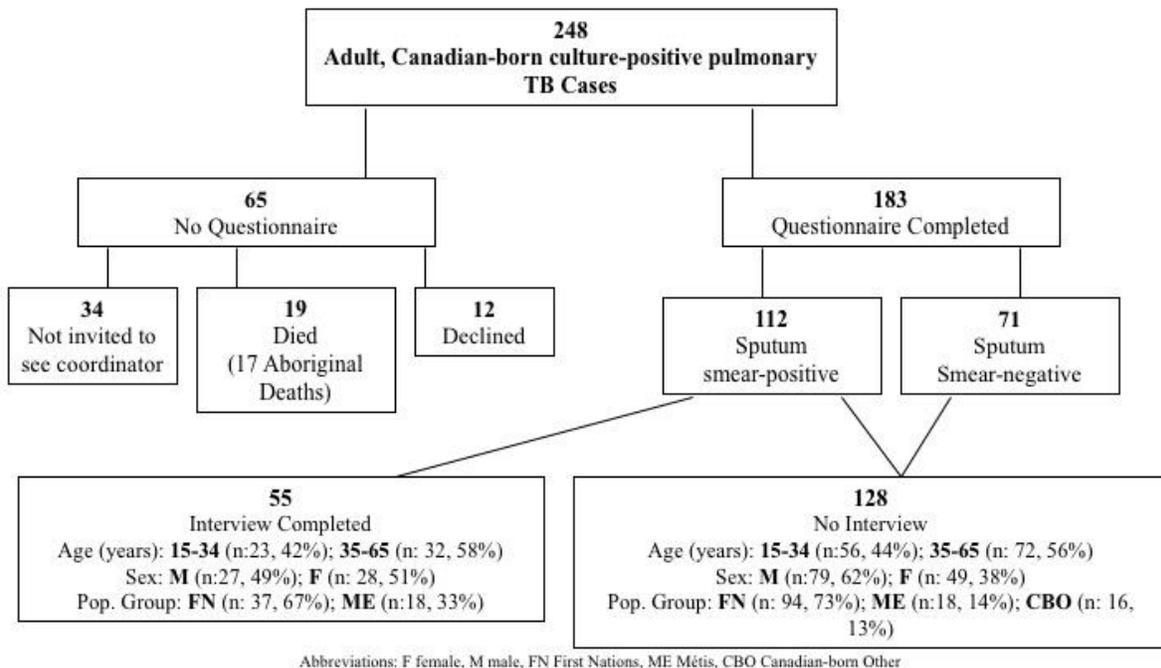


Figure 1. Determinants of Tuberculosis Transmission study sample and participants.

As detailed in Table 1, interview participants ranged in age from 17 to 63, with males and females equally represented. Two thirds were First Nations, and one third were Métis. More than three quarters of participants reported fluency in an Indigenous language. Most lived in a rural area with 45% reporting on-reserve residency, while 38% resided in an urban centre.

Table 1

Interview Participant Sociodemographic Characteristics and Circumstances Associated With Tuberculosis

Characteristic		Total (n = 55)	Total (%)
Age	Average age	38	–
	Max. age	63	–
	Min. age	17	–
Sex	Female	28	50.9
	Male	27	49.1
Population group	First Nations	37	67.2
	Métis	18	32.8
Marital status	Married/common law	20	36.4
	Divorced/separated	9	16.4
	Single	26	47.2
Education	High school or further	10	18.2
	No high school diploma	45	81.8
Employment	Employed at diagnosis	20	36.4
	Not employed at diagnosis	35	63.6
Language	Fluent in an Indigenous language	43	78.1
Residence	Urban	21	38.2
	Rural on-reserve	25	45.4
	Rural off-reserve ^a	9	16.4

^a Includes residence in a Métis settlement/Northern Village or rural town/village/hamlet.

Participants signed an English-language consent form. Interpreters were available upon request. Caregiver consent was obtained for participants under the age of 18. All interviews included in this analysis were completed in English, audio-recorded, and transcribed verbatim. A semi-structured interview tool was designed to capture participants’ current experience and perceptions of TB, their life history as it relates to the social determinants of health, and their general ideas about health. The interview tool was developed in an iterative review process with members of the PNCs, who also provided guidance on appropriate implementation of the tool. Progress was reported one to two times per year to the PNCs, who provided ongoing guidance during the analysis and interpretation. The findings highlighted in this paper were presented and discussed at PNC meetings, where they were approved for dissemination.

The interview tool consisted of open-ended topics of inquiry (with probes used as appropriate) that included participant life history and home, a typical day before becoming ill, characteristics and conditions of sick and healthy people, participant experience of becoming ill

with TB, and other illnesses that may be of concern in participant families and communities. This approach allowed participants to discuss whatever they considered important to their TB experience. The PNCs advised the team that that this conversational type of approach would be preferable (Kovach, 2009).

The interviews became avenues of exploration for participants who were often, for the first time, trying to make sense of their current TB experience and its impact on their lives. Participants had the opportunity to review their transcribed interviews prior to analysis. One participant requested the opportunity to review and did not return any changes to the original transcript.

Due to differences in the provision of healthcare described earlier, participants were receiving treatment and care for TB in different ways. In Alberta and Manitoba, many were hospitalized at the time of their participation in this study, so they were interviewed there. In Saskatchewan, interviews took place in a variety of locations that included the hospital, patient homes, a hotel, a research space, a correctional facility, and a rural health clinic. A mobile TB clinic allowed patients in Saskatchewan to access virtually all their TB treatment in their home communities. We anticipated that these differences might influence interview responses, so attention was paid to this possibility during analysis. While some differences in the types of frustrations participants expressed about the treatment experience were noted, the overall life experiences they described remained remarkably consistent.

Analysis

Interview transcripts underwent a multistage and iterative coding process among a five-member qualitative sub-team that included the three provincial research coordinators/interviewers and two qualitative co-leads. There was one Indigenous member of this team (co-author KM), who, as a provincial research coordinator, significantly shaped qualitative data collection and analysis. Each member of the coding team individually conducted an initial open coding process. The team met frequently to create a common code list, ensuring that they were sensitive to relevant literature on experiences relating to TB, social determinants of population health, and a First Nations health and determinants framework (AFN, 2006, 2013). The in-person meetings included opportunities for peer debriefing to ensure analytical rigour and to discuss findings. The coding process was managed using ATLAS.ti 5.2.

The open coding process revealed a clear point in each patient story where participants described feeling sick enough to seek healthcare. To understand the context for arriving at this point, we conducted a focused analysis driven by the following questions: What made participants decide “something is wrong with me and I need healthcare”? What were they feeling around that time? What was the “usual health” from which they decided they were unwell enough to seek healthcare? How did they describe a healthy person? The answers to these questions are the focus of this paper. In addition, questionnaire responses for the 55 interviewees were analyzed descriptively to summarize sociodemographic information.

Results

In seeking to understand Indigenous patients’ explanations of when they seek healthcare to deal with troubling symptoms, it is important to have some appreciation of their perceptions of good health generally, and of their usual health and circumstances leading up to their current TB illness.

Good Health, Usual Health, and Getting Sick

Overwhelmingly and consistently for all participants, healthy people were described as energetic, engaged, and essentially happy. A Saskatchewan participant described it this way: “If I was healthier my house would be clean every day. I would go to school ... I would walk around everywhere. Go visit. I would have a smile on my face every day.”^{SK001} There were also reflections on the links between health, happiness, stability, and being surrounded by family and friends. A healthy person is “someone that’s happy, like stable in life, has a lot of things happening to keep him or her busy, friends, family.”^{AB021}

These reflections about what an individual in good health looks like were not seen in participant descriptions of their usual state just prior to becoming sick with TB. In their interviews, participants described feeling generally unhappy and inactive. One Saskatchewan participant explained, “I don’t feel like associating with other people and I just want to sleep.”^{SK001} A Manitoba participant described coughing and weight loss but initially attributed the symptoms to alcohol use: “Started coughing couldn’t stop ... quit drinking—still not feeling good, losing weight.”^{MB012} A third participant described feeling lazy, linking this idea with aging: “But generally, I’ve been for the last couple of years, I guess I’ve been kind of lazy, maybe because I am getting old.”^{MB014} An Alberta participant reflected,

I’d wake up, I’d have to always spit up a lot of sputum, and in the morning I ... I just thought it was like either my smoker’s cough or, you know, like just a mild cold that I could get rid of. I’d take either an Advil or Aspirin and keep on going, and yeah, I never suspected it would be TB or something, well, serious enough.^{AB021}

The responses participants provided to the questionnaire provide further context (Tables 1 and 2). Participants had a low level of educational attainment, with 82% not having completed high school. Over 60% were unemployed. Almost half (47%) reported being single, with another 16% indicating they were either divorced or separated. Thirty-six percent were either married or in a common-law relationship. Many (36%) reported living in crowded housing with perceived poor air quality. About one third of the participants had been incarcerated within the last 2 years. In addition, 38% were already dealing with one or more chronic conditions such as diabetes, HIV infection, or hepatitis C, and many were struggling with substance misuse (alcohol, tobacco, injection drugs, prescription drugs).

Table 2
Tuberculosis Risk Factors of Interview Participants

TB Risk Factor		Total (n = 55)	Total (%)
Incarceration (last 2 years)	Yes	18	32.7
	No	37	67.3
Crowded housing	Crowded (> 1.5 PPR) ^a	20	36.4
	Not crowded (≤ 1.5 PPR) ^a	35	63.6
Perceived air quality	Poor ventilation/mould	20	36.4
	Fair to good air quality	30	54.5
	Don't know/no response	5	9.1
Alcohol	Alcohol-dependent ^b	25	45.5
	Not alcohol-dependent ^c	30	54.5
Cigarette smoker	Yes	44	80.0
	No	11	20.0
Other substance use	Illicit drugs ^d	32	58.2
	None	22	40.0
	No response	1	1.8
Comorbidity	Yes ^e	21	38.2
	No	34	61.8

^a People per room.

^b Adapted from the DSM-IV criteria for dependence (American Psychiatric Association, 2000).

^c Includes those who drink but are not alcohol-dependent and those who do not drink alcohol at all.

^d Includes injection drug and prescription drug misuse at the time of diagnosis.

^e Comorbidities reported by 21 participants include Type 2 diabetes (10), HIV/AIDS (5), hepatitis C (2), asthma (1), and other (11). Some respondents reported more than 1 comorbidity.

Symptoms linked to pulmonary TB include cough (for a period of weeks and possibly with blood), chest pain, loss of appetite, weight loss, fatigue, night sweats, and fever (Long, 2015). Participants did report experiencing many of these symptoms (Table 3).

Analysis of questionnaire responses revealed that almost 93% had a cough, 80% weight loss, and almost 70% night sweats and fever. About 58% indicated other symptoms, which in interviews were captured with phrases such as “takes too long to do something” (Table 3). Several of these symptoms were also associated with their usual state of health, which was far from the ideal health they had also described. Essentially, these were symptoms that would more likely stand out as unusual earlier if participants had been living the life of a healthy person as they described. There was, however, awareness that some of the symptoms they were familiar with in their everyday lives had worsened. As the transition to poorer health was examined further, three interrelated themes were uncovered:

1. location of TB symptoms in usual day or life events,
2. symptom management to keep going, and
3. fear of being really sick.

The interviews showed that in the weeks and months before their TB diagnosis, one or more TB symptoms were noticeable. One person described his transformation in this way: “Me, I was just skinny and long-haired, and looked terrible, all right!”^{AB007}

Table 3
TB Symptoms Described by Participants in Questionnaires and Interviews

Source	TB Symptom	Total (n = 55)	Total (%)
Questionnaire	Cough	51	92.7
	Fever	38	69.1
	Night sweats	37	67.3
	Weight loss	44	80.0
	Fatigue	16	29.1
	Chest pain	9	16.4
	Other	32	58.2
Interview	Sleepy		
	Takes too long to do something		
	Sore ribs, chest pain		
	Bones were sore, muscles were sore, back sore		
	Get really tired, really fast		
	Nose was stuffy, congested		
	Heartburn		
	Couldn't breathe		

Participants linked experiences of their usual day or life events to explanations for the symptoms. Fatigue, for example, was linked with general unhappiness. In many of the interviews unhappiness related to a recent personal loss, such as a relationship, or death of a friend or relative. Coughing and smoking were associated in many stories. Participants struggling with substance use linked their weight loss or lack of appetite to this issue. The words participants used to describe their feelings around the time they began to feel really sick (Table 3) were also reflections of their usual day, but were escalating to interrupting that day. The theme of symptom management emerges at this point. As participants went on to describe worsening symptoms, many sought to manage them either by sleeping or by medicating in some way. The narrative given by the following participant covered a winter season during which three major TB symptoms—fatigue, coughing, and weight loss—were experienced as worsening. Of significance

is that this participant’s story, as did some others, included multiple contacts with health professionals:

And I started coughing lots. I couldn’t, I can’t walk long ways. I get tired really fast so I figure it’s just the flu, you know, and then it just went on and on like that ... then I started taking these, uh, seeing doctors about painkillers. I started taking Tylenol 3s [acetaminophen with codeine] ... That kept me going. I lived with this thing all winter like that ... I was boarding with my sisters ... I slept lots. I didn’t even eat very much. I smoked a lot of cigarettes. AB006

For a time, participants could “keep going” with behavioural coping strategies, such as sleeping, or taking cold and pain medication. The third theme, fear of being really sick, also drove participants to symptom management to keep going, even when there was finally the recognition that they were really unwell, that their condition was serious. Participants expressed a constellation of fears. Women, some of whom were single parents, were reluctant to even visit the nursing station down the road in their remote communities, because they were primary caregivers for children or others and were not sure who could care for them even for a short absence. Some were afraid of losing their jobs, especially in workplace environments hostile to Indigenous workers. One man stated:

I want to keep working, because Aboriginals were getting fired there and I, if I’m going to call in sick, (they’ll) think that it’s just from drinking. I started brainwashing myself like that, you know. I don’t want to go home, I’m not that sick, so I just kept going to work like that. AB040

Others were afraid of being diagnosed with an infectious illness, recalling or being told stories of what happened to these individuals in the past:

I’ve heard of this where, where you have a hospital in ____ where I knew this one Inuit guy that was stuck there for about three years. It took him over three years. He told me that. He says, “If they take, they take you and throw you in there, you won’t get out [of] there.” AB018

Falling Down

Many participants described arriving at a point in their illness experience when they were no longer able to get through a day of usual tasks, even with the strategies they had implemented to manage symptoms. At this point, participants described literally falling down, and being left with no other choice:

I even knew I had to come to hospital, but I just couldn't face myself that I had to. And finally, finally, when I started falling down I, I had no choice then.” AB018

Friends, family, and others played an important role in convincing participants to see a health professional. The mother of one young man noticed her son falling asleep through the day. It was the brother of another participant who noticed his weight loss, telling him he looked sick. A young woman's friends teased her that she had lost so much weight that she would blow away when she went outside. Nephews and nieces told one Auntie that she “might even have the disease” (referring to HIV). One participant noted that a family member told her, “Sometimes you look like it is not you.” At this point, she said, “That day they talked me into going to ... hospital.” AB018

Discussion

TB Symptoms Experienced in Context

Interviews with TB patients revealed some explanations for the advanced state of TB disease. Participants' descriptions of healthy people were not characteristic of their own lives in the weeks and months leading up to their diagnosis. Symptoms that in healthier individuals would stand out sooner as something new were initially interpreted as the worsening of a usual state of health associated with influences such as smoking or substance misuse. Participants also discussed recent personal losses in the form of relationships or deaths. Sleeping, withdrawal from community participation, and substance misuse were some mechanisms participants used for coping with challenges and symptoms.

Embedded in the life histories participants described, the recognition of symptoms as unusual and alarming can clearly be delayed. It is important to recognize that TB symptoms are non-specific and do not present all at once, and like other slowly progressive diseases, symptoms are universally recognized later in the disease course by patients and healthcare providers (Bastin et. al., 2010; Long, 2015; Ward, Marciniuk, Pahwa, & Hoepfner, 2004). The finding that TB symptoms were initially associated with other explanations, including other illnesses such as colds and flu, has been reported elsewhere (Auer, Sarol, Tanner, & Weiss, 2000; Jaramillo, 1998; Liefoghe, Baliddawa, Kipruto, Vermeire, & De Muynck, 1997; Mann Woith & Larson, 2008; Nnoaham, Pool, Bothamley, & Grant, 2006). Participants' stories also captured experiences consistent with a systematic review that identified delay in the diagnosis and treatment of TB because of the coexistence of chronic cough, rural residence, low healthcare access (geographic or sociopsychological), poverty, substance use, symptom management, and stigma (Storla, Yimer, & Bjune, 2008). Even at the point that participants realized they were quite unwell and accessed healthcare, they received treatment for symptom management (e.g., Tylenol 3), suggesting their symptoms were not associated by their providers with TB. In addition, fears associated with caregiving responsibilities and job loss resulted in some participants attempting

to manage symptoms (sleep, painkillers) for as long as possible to just keep going. Turrís (2009) similarly found that for women seeking care for possible symptoms of cardiac illness, decisions about treatment seeking were influenced primarily by the contexts of their lives as mothers, daughters, and wives and only secondarily by their symptoms. Many of these explanations are in contemporary experiences of the social determinants of health, including access to healthcare, which the Assembly of First Nations population health framework (AFN, 2006, 2013), links to determinants of historical significance.

Stories shared by Indigenous participants in this research certainly point further upstream from their life circumstances today to the effects of historical colonization and colonialism. Møller (2005, 2010) explains that while there may be cultural differences in the way that Aboriginal Peoples and Western healthcare view body, health, and disease, these differences are less important than the effects of colonization and colonialism in the way that TB is experienced and given meaning, and care is accessed. Some participants in our study expressed general feelings of hopelessness and despair about their TB experience in the context of their lives. In a related analysis, we contextualized these expressions through a Cree fictional character called Old Keyam, who embodied the struggles of Indigenous people within colonization policies (McMullin et al., 2012).

The colonization of Indigenous people, including residential schools, and the intergenerational trauma connected to this, has resulted in collective contemporary challenges to well-being (Aguiar & Halseth, 2015) and to the state of healthiness that participants described as “happy, stable, busy.” As we have elaborated elsewhere for participants in this study (Komarnisky et al., 2016), and as Møller (2005, 2010) has described for the Inuit, related studies among contemporary Alberta TB patients also point to the legacy of the TB sanatorium era as contributing to delays in seeking diagnosis and treatment, and a general apprehension about healthcare (Gibson, Cave, Doering, Ortiz, & Harms, 2005; Moffatt et al., 2013). Research in urban Montreal reported similar findings on the impact of negative memories and experiences rooted in colonial treatment strategies as being significant for the mistrust Indigenous participants expressed towards the contemporary healthcare system (Brassard, Anderson, Menzies, Schwartzman, & Macdonald, 2008; Macdonald, Rigillo, & Brassard, 2010). Elliott and de Leeuw (2009) reported misunderstandings in encounters between family doctors and Aboriginal patients that also highlight the relevance of sanatorium history as well as the impact of contemporary negative images of “drunken Indians” that stereotype and pathologize Aboriginal people. These observations are not new (O’Neil, 1989) and continue to be widely experienced (Allan & Smylie, 2015; Jacklin et al., 2017).

The consequence of all of this, as we have seen in this study, is that participants describe a point in their illness experience when they are literally falling down. In addition, friends and family members who also notice their physical deterioration play an important role in pushing them to pursue healthcare access. Early symptom recognition in association with TB is clearly important for preventing serious disease and interrupting transmission. It is well established that

the longer the duration of symptoms in the source case, especially if that source case is smear-positive, the greater the risk of transmission (Lohmann et al., 2012). Health Canada (2012) reported that, in First Nations reserves in Canada, symptomology is the most common method of case detection (57.3% of cases). Between 2000 and 2008, 64.6% of on-reserve cases in Alberta, 59.8% of cases in Saskatchewan, and 53.5% of cases in Manitoba were detected in this way (Health Canada, 2012, Table 4).

“Tipping Point”

A concept originating in physics, the tipping point simply refers to the notion of adding a small amount of weight to a balanced object until it topples over. Sociologist Morton Grodzins (1957, 1958) and economist Thomas Schelling (1969, 1971, 1978) adapted the concept as a powerful metaphor for human group behaviour, in their case specific to neighbourhood racial segregation. The concept has since been subject to further scholarly consideration (e.g., Clark & Fossett, 2008; Zhang, 2004) and popularized (Gladwell, 2000), and the term “tipping point” has become common in the English lexicon.

We find the metaphor similarly powerful for interpreting the moment patients recognize their symptoms as unusual. The tipping point effectively captures the cumulative small actions, incidents, and experiences patients describe that tip the balance of symptoms being associated with usual health to being exposed as a new or more severe illness. The moment of recognition that participants in this study experienced caused them to seek healthcare, or for those who had already done so, to persist, often with the support of friends or family. Of significance to our analysis is that the tipping point for the participants in this study was simply *too late*. Explanations for the late arrival to a tipping point for Indigenous participants are in a common context that includes colonization and its influences on their contemporary experience of social determinants of health (AFN, 2006, 2013). This leads them as a group to experience poorer overall usual health than non-Indigenous people in Canada and, as highlighted earlier in the Discussion, potentially avoid accessing healthcare. Tipping points need to be shifted back to identify illness well before Indigenous people afflicted with TB become so sick that they fall down, and to reduce the spread of TB disease among Indigenous people and communities on the Canadian Prairies.

Many of the participants in this study were from communities where the occurrence of TB is not unusual (Long et al., 2013). At the same time healthcare worker vacancies in these communities are not uncommon and continuity of care is typically lacking. Although there are some Indigenous healthcare workers, there are not nearly enough. Education about TB, how it presents, its relationships to other illnesses (e.g., HIV/AIDS), stigma, cultural competency, and patient safety represent pressing needs, especially in high-incidence communities. Orr (2011a, b) identified these and other issues in a two-part systematic review of adherence to tuberculosis care in Canadian Aboriginal populations. While the focus of these reviews was on adherence to treatment, these same findings are also relevant to moving back the tipping point for TB

symptom recognition. In her reviews, Orr (2011a, b) points to the responsibility of healthcare personnel and the system to build quality relationships with Aboriginal people and communities, and to create TB programs that consider the complex interactions between health systems, societal factors, and personal factors. As this study shows, these influence tipping points and access to healthcare. Finally, Orr (2011b) also explains that TB programs should have meaning consistent with Indigenous beliefs about causation and care. Citing his vivid recollection of a story of the achievement of wellness shared by an Indigenous community member co-infected with TB and HIV, one co-author (MK) has suggested that late biomedical treatment-seeking behaviours may be linked to what his research on wellness has revealed as a capacity to achieve wellness outside biomedical intervention (Macklin, Beaudoin, Lu, King, & King, 2014).

These complexities are consistent with Waisbord’s (2007) argument that TB communication programs should adopt a “social rationality” perspective that draws on nuanced understandings of community TB experiences. These understandings may draw on systemic deficits as well as capacities outside Western healthcare. It is important that the latter is not simplistically interpreted as blaming the individual for delayed recognition of symptoms as possible TB, or delayed access to biomedical healthcare. In addition to the responsibilities of healthcare workers and the health system, strategies to link symptoms to possible TB earlier must include family and friends, since they are often the first to notice changes (e.g., more coughing, more sleeping, weight loss). Furthermore, they play a key role in supporting sick individuals to seek healthcare.

Finally, these ideas are very much centred on working within the status quo life experience of the Indigenous people who shared their TB experiences with us. Truly moving back the tipping point will require recognition that the “usual” experience of health from which symptoms of illness are interpreted should more closely align with the aspirations for good health participants identified. For Indigenous Peoples, this requires action on the contemporary social determinants of health, and on the intergenerational legacy of colonization (Greenwood et al., 2015; Reading & Halseth, 2013). Ideally, this would follow a population-specific framework, such as that produced by the Assembly of First Nations (AFN, 2006, 2013), which pays explicit attention to determinants such as colonization and self-determination that are not included elsewhere, such as the determinants that guide public health policy in Canada (Public Health Agency of Canada, 2013).

Limitations and Conclusions

Effectively interrupting TB transmission involves several people (the TB-infected individual, those with close relationships to that individual, and healthcare providers), and multiple tipping points, all of which need to be moved back. This study provides some understanding for the first of these—the tipping point for Indigenous TB patients on the Canadian Prairies.

This narrative is important and should be privileged as it was here. Patient and community voices are too often absent in the consideration of policy and program interventions. The stories in this study show that patients were spending time with friends and family. In addition, there were contacts with healthcare professionals and with the healthcare system in the weeks or months prior to a TB diagnosis, as they received prescriptions to manage various symptoms.

Moreover, though we have not addressed it in this paper, the interviews revealed that the tipping point for participants did not always translate into a timely diagnosis of TB. We did not conduct interviews with family members of TB patients or with healthcare providers who would have allowed us to probe this fully. These are avenues for future research that would provide further insight into the tipping points for all involved in achieving an earlier TB diagnosis.

Finally, there is a need to look at the structures and systems that produce and perpetuate inequitable distribution of the conditions that produce population-level disparities in the circumstances of usual health.

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