

## Commentary

# Tuberculosis among First Nations, Inuit and Métis children and youth in Canada: Beyond medical management

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### Abstract

First Nations, Inuit and Métis people in Canada continue to be disproportionately affected by tuberculosis (TB), a disparity rooted primarily in factors such as poverty, crowded and inadequate housing, food insecurity, and inequitable health care access. Historical TB control practices in Canada have contributed to stigma and discrimination toward those with the disease, as well as fear and mistrust of the health system. These individual and system-level factors result in delays in TB diagnoses, ongoing transmission, poorer outcomes, and lower treatment completion rates. Children are especially vulnerable, as they are more likely to develop disease once infected with TB bacteria and to experience life-threatening conditions such as TB meningitis. Paediatric health professionals can help to increase TB awareness and literacy, reduce stigma and discrimination, and ultimately, improve the quality and uptake of services for treatment and prevention in families and communities at risk. They can also advocate for sustainable, community-driven TB elimination strategies that incorporate First Nations, Inuit and Métis principles of wellness, healing and self-determination.

**Keywords:** *Child health; First Nations; Indigenous; Inuit; LTBI; Métis; Tuberculosis; Social determinants*

### UNDERSTANDING THE DISEASE

Tuberculosis (TB) is a communicable disease that typically spreads by inhaling airborne droplets containing *Mycobacterium tuberculosis* bacteria. Once inhaled, TB bacteria typically become dormant in the presence of a mature and well-functioning immune response. This asymptomatic condition is known as latent TB infection (LTBI) or 'sleeping TB' (1).

Children, especially those under 5 years, may not be able to mount the immune response necessary to create or to maintain dormancy. After a child is exposed to someone with contagious TB, the disease can develop rapidly, typically with a respiratory component, and sometimes in life-threatening forms such as miliary TB and TB meningitis (2). Diagnosing, treating, and preventing TB in children can be challenging, and failing to do so can have devastating consequences for children, and their families, communities, and health care providers (2,3).

### UNDERSTANDING THE MAGNITUDE OF THE ISSUE

Although TB has been nearly eliminated in non-Indigenous people born in Canada, it is a public health crisis in some First Nations, Inuit and Métis communities. Living conditions, health inequities, historical traumas, and stigma help sustain high incidence rates of active TB in some Indigenous communities (4). Consider these population incidence rates for 2016 (5):

- 0.6 per 100,000 among Canadian-born, non-Indigenous people;
- 23.8 per 100,000 among all First Nations people;
- 170.1 per 100,000 among Inuit;
- 2.1 per 100,000 among Métis people.

Unlike active TB disease, LTBI is not well established as a reportable condition. Lack of data on the background prevalence

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of LTBI among First Nations, Inuit and Métis at any level—nationally, by province/territory, or by community—further complicates efforts to detect, prevent, and ultimately eliminate TB among those most at risk (4). It also underscores why health care providers serving First Nations, Inuit and Métis families should inform themselves about local TB context and epidemiology.

## UNDERSTANDING THE ROOT CAUSES

### Social determinants

TB is often referred to as a social disease with medical consequences, because the drivers of TB have more to do with social and economic factors than with the pathogen itself (6). TB thrives where there is poverty and health inequity. Living conditions that contribute to high rates of TB among First Nations, Inuit and Métis include: crowded and poor quality housing, food insecurity, and barriers to health care access (6).

The degree of household crowding and frequency of exposure to indoor molds and other air pollutants such as tobacco or cannabis smoke increase TB risk (7,8). Chronic food insecurity can lead to malnutrition and increased risk for development of TB after infection with TB bacteria (9). Barriers to health services in remote First Nations, Inuit and Métis communities such as geography (e.g., remoteness and precarious transportation infrastructure), and chronic shortages and high turnover of health care personnel can result in delays in diagnosis, initiation of airborne isolation precautions, and treatment. Such delays also encourage ongoing transmission, result in secondary cases, and amplify a largely undefined prevalence of LTBI (4).

### Historical trauma

From the 1940s through the 1960s, before widespread availability of medications to treat TB, many First Nations, Inuit and Métis people endured lengthy forced confinement in TB hospitals or sanatoria (10). Children were sent to sanatoria hundreds or thousands of miles away from their parents and other loved ones, community and culture, often for years (11,12). Some young children who recovered from TB were sent directly from TB sanatoria to residential school, adding to their trauma. Conditions in residential schools exacerbated the epidemic, and have been referred to as ‘breeding grounds’ and ‘incubation wards’ for TB (13).

Families may not have been informed about the well-being or whereabouts of children taken to sanatoria (12,14). Some children died, and families may not have known where they were buried. Children who returned to their home communities may not have understood the language, skills, or social norms anymore (14).

Many adults and elders in First Nations, Inuit and Métis communities today grew up during the sanatoria age. These

experiences continue to affect how individuals, families, and communities perceive the potential consequences of being diagnosed with TB (14).

### Stigma, discrimination, and racism

The perception of stigma can lead to discrimination from others and self-stigmatizing by those with TB, leading to consequences such as social exclusion, and loss of housing or income (15). People with TB may feel ‘unworthy or guilty’ (16), which can lead to depression and self-imposed emotional or physical isolation from family and other sources of support. These consequences can be powerful influences on whether people seek TB screening for themselves and their families, and how quickly care is sought when TB symptoms develop. For First Nations, Inuit and Métis people, delays in seeking care may be exacerbated by perceptions of or experiences with racism in the health system (17).

## WISE PRACTICES FOR HEALTH CARE PROVIDERS

Assessing children and families for TB requires providers to respect the mental, social, and financial impacts raised by even the possibility of a diagnosis. Words and actions by a health professional can inadvertently perpetuate misconceptions and amplify feelings of stigma and discrimination (17).

Communication can be a substantial barrier to receiving and providing appropriate care, particularly when children and families and their health care providers do not speak the same language (or dialect) fluently, or when clinicians miss subtle nonverbal communication.

### A note about data and Métis communities

While national data suggest that rates of TB among Métis people are similar to those reported by the general population, a lack of Métis-specific information and incomplete TB surveillance make it challenging to understand the true impact of TB on these communities, particularly in Saskatchewan. Poverty, crowded living conditions, coinfections with HIV, diabetes, and malnutrition are among the factors that contribute to the endurance of TB in Métis communities, along with cultural beliefs and barriers that limit access to health services.

“It is assumed that, in northern Saskatchewan, TB is an exclusive problem for First Nations people,” says Clara Morin Dal Col, Métis Nation Minister of Health. “It is a challenge to identify Métis from First Nations TB cases when there are families with Métis and First Nations ancestry or intermarriage, where both communities share the same geographic location and the same social determinants of health disparity.”

Minister Morin Del Col adds that structural changes are needed to meet the health care needs of Métis people: “Many Métis people who live in rural and remote communities do not have easy access to health care facilities. They have to find the money to pay for their transportation to see specialists and to get observed TB treatment in larger urban centres.”

### Toward TB elimination

Reducing TB rates among First Nations, Inuit and Métis communities is a short-term goal. Real success means improving the socioeconomic conditions that have allowed TB to proliferate—poverty, residential crowding, food insecurity, and poor access to health care. This can only be achieved through complex, long-term, and multisectoral work (6,14).

It is critical that Canada's health systems be transformed towards Indigenous self-determination. That means supporting First Nations, Inuit and Métis communities to develop innovative and successful health and wellness programs that better meet their needs based on a holistic and culturally based worldview.

The Truth and Reconciliation Commission calls on governments and institutions to work with and alongside Indigenous peoples to achieve health equity for First Nations, Inuit and Métis communities (18). Here are some tangible ways institutions and individual health care providers can work toward eliminating TB in their communities.

### What can institutions—including hospitals and universities—do?

#### Embrace the calls to action of the TRC

Collaborate with First Nations, Inuit and Métis groups to create an organizational culture that addresses the continued effects of colonialism on the health system, helps close gaps in health outcomes, and works to establish respectful relationships (18). For example:

- a. Ensure all staff working with First Nations, Inuit and Métis children, youth and families complete cultural safety training so that they understand the historical and current context of TB, and that similar education is incorporated into undergraduate and postgraduate medical curricula.
- b. Consult with First Nations, Inuit and Métis communities to seek solutions that minimize barriers to timely diagnosis and completion of treatment for active TB and latent TB infection. These could include bringing care closer to home, using patient navigators, and developing culturally appropriate operational practices (e.g., appointment recall management).
- c. Incorporate First Nations, Inuit and Métis healing practices into the care pathway for Indigenous patients and families.
- d. Increase the number of First Nations, Inuit and Métis people working within the organization.
- e. Encourage interested health practitioners—by providing time and space—to develop sustainable models of Indigenous-focused care.

### What can you do to improve your ability to provide care?

1. **Know the TB context and epidemiology of the communities you serve.** In particular, learn about which groups are at increased risk for TB. You may need to establish a relationship with local public health providers, who are typically involved in delivering TB programs.
2. **Learn about the history of health care and TB control for First Nations, Inuit and Métis people in Canada, how these practices extend into the present, and how they shape your role as a health provider.** Doing so will help you to better understand how historical trauma can affect the relationship between you (as a representative of the colonial health care system) and the people you serve.

### What can you do for your patients and their families?

1. **Work with First Nations, Inuit and Métis families to codevelop TB care plans that meet their needs.** Recognize the need for flexibility, and ensure that care plans are mutually acceptable and reflect the health and social challenges, life priorities, strengths, and support systems of the patient and family. Build in access to supports that enable sustained participation in care and recovery, such as transit passes, child care, or grocery vouchers. When appropriate, refer to wellness support programs for parents or caregivers. Choose treatment regimens that improve adherence.
2. **Share culturally appropriate information on TB.** Increasing awareness and understanding of TB and how it is treated now will help to change how people think about TB, reduce stigma and discrimination and ultimately, increase uptake of screening and treatment in communities at risk. Incorporating First Nations, Inuit and Métis knowledge and ways of learning (e.g., oral versus written) will help, as will ensuring access to the information in the client's preferred language.
3. **Create safe spaces when caring for First Nations, Inuit and Métis patients and families.** Be aware of how your communication style and the questions you ask might be interpreted. In situations where it is important to explore health challenges or social networks, it can be helpful to allocate extra time to establish a helping relationship and build trust.

### What can you do for the wider community?

Contribute to efforts being made at all levels to improve social determinants of health for Indigenous people in Canada. Connect with your local, provincial/territorial, and federal leaders to show support for action and funding in these areas. Consider joining or supporting advocacy groups, such as Stop TB Canada (StopTBCanada.org) and RESULTS Canada (ResultsCanada.com).

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