

Editorial

The Enduring Plague: How Tuberculosis in Canadian Indigenous Communities is Emblematic of a Greater Failure in Healthcare Equality

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ABSTRACT

Despite global strides made in prevention and treatment, tuberculosis (TB) remains an acute problem for Indigenous people in Canada. TB affects Indigenous communities at significantly higher rates than the general Canadian population, for whom it is a disease of the past. This paper suggests how colonialism and its history of violence have shaped the face of TB in Canada, and thus how TB is a telling point of analysis for considering the lack of equity and equality in healthcare delivery in Canada.

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Tuberculosis (TB) is, and always has been, a disease of poverty [1]. The bacterial infection that causes TB is widely associated with the conditions of poverty, including overcrowding, smoke inhalation, weak social support systems, and a lack of nutritious food [2]. At this point in its history, TB has been eradicated in many places and is now highly concentrated in developing countries, where it continues to devastate those who cannot afford to prevent or treat it [3]. As a nation, Canada shows the expected low TB rates of the rich and developed world, with about 1700 cases per year [4]. However, a dangerous truth persists, obscured by the whitewashed averages of a wholly unequal nation. Indigenous persons in Canada have almost 300 times the risk of getting TB than non-Indigenous persons, and despite making up only ~4% of the Canadian population, they represent 19% of all the TB cases, with foreign-born Canadians accounting for 70% [4]. These rates are most striking within the Inuit population, for whom a disease the rest of Canada forgot about in the 1900s continues to cause pain [4]. The deaths of Ileen Kooneeluisie in January of 2017 and Gussie Bennett in March of 2018 led health journalist Picard [5] to comment, “These deaths are, in many ways, a perpetuation of Canada’s shameful history of neglect of Indigenous peoples.” These inequities highlight the larger issue of Indigenous rights in Canada; particularly as concerns healthcare and health access. Thus, the consistent recurrence of TB among Indigenous peoples in Canada provides a profound point of analysis for the broader failures of Canadian health culture. As Kevin Patterson wrote, “There is no clearer evidence of the maldistribution of wealth and of social services in Canada...than the tuberculosis epidemic under way in the Arctic.” [1]. There is no reason for anyone in Canada in 2018 to die of a disease that has been curable since the mid-20th century, and thus what defines this burden is

not a lack of science, but rather a lack of cultural understanding and a fundamental neglect of Indigenous suffering. This paper therefore analyses why TB persists among the Indigenous population in Canada, in order to consider Indigenous healthcare as a whole, and demonstrates how a colonial legacy of mistrust and cultural blindness remains endemic in Canadian healthcare to this day.

The Canadian public healthcare system is a matter of pride for many Canadians. Socialised health services, to which all citizens’ taxes contribute, represent an essential acknowledgement on behalf of Canadians of a need to help those who require support. The Canadian health system reflects a main tenet of universal health coverage; that those who need help deserve to access it and should not be left in financial ruin because of it [6]. The principle of health for all emerged in the 1970s at the World Health Organization’s Alma Ata Conference [6]. Health is expensive, but at the core of the health for all movement was the acknowledgement that it was both worth the price and deserving of better funding. This fundamental understanding of deservingness and health as a basic human right is why wealthier Canadians, those who can afford private services and insurance, subsidise those who cannot. This group-support mentality is also represented by Canada’s liberal attitude at home and abroad. However, equality is not equity. Distributing one healthcare system across the whole of the country, and expecting it to be sufficient for all those who need help, is ignorant of the unique needs certain communities and populations are facing, namely those that are foreign-born and Indigenous [7]. Sylvain [8], in her discussion of the San people of Southern Africa, shed light on this homogenising nature of globalisation and development. She writes that understanding ethnicity often only amounts to “... universalistic (and essentialist) assumptions about psychological needs.” Generalising need is not a reflection of true understanding, and obscures important diversity. Without acknowledging the

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importance of a person's culture, it is impossible to offer personalised, appropriate, and robust healthcare services, especially when these customs are such an important part of the healing process as they are for many Indigenous people [7]. Considering only the Canadian experience as a whole purposefully overlooks a reality of difference and integrates people only by minimising their individual conditions and needs. It is not enough to claim that because healthcare is free in Canada, that all Canadians can and do access it. It is also not enough to offer the same basic services to all, because some people need more or different help than others. Not only is healthcare in practice not distributed equally to all people in Canada [9], but even if it were, the cultural wellness needs of Indigenous people would still not be met, because Canada does not truly appreciate that they exist and are worth supporting. This cultural ignorance stems from the Canadian colonial experience; one that is as enduring as it is damaging.

People like to refer to the 21st century as postcolonial, relegating the experiences of colonised people and lands to nothing more than a problem of the past [10]. The Canadian colonial experience is one of injustice, wherein the British and French stole land from the Indigenous people living in what is now Canada, and through both direct and indirect violence began a long history of dominance over their communities. Perhaps one of the most famous indirect forms of violence driven by colonial interaction was the rapid and deadly spread of smallpox across most of North America. Smallpox however was not the only disease that the European settlers brought with them; they also carried strains of TB, and thus, TB has been endemic in Canada since colonisation [1]. Canadian colonial history is also shaped by more direct forms of violence and control, including the horrifying legacy of residential schools and the forced removal of children from their families. The residential school system was established in the 19th century to forcibly assimilate First Nation, Inuit, and Métis children into settler colonial Canadian culture [11]. The goal was to limit and eventually eradicate Indigenous customs, which were seen as detrimental to Canadian growth and social progress [11]. In these schools, children were emotionally, sexually, and physically abused, and many never saw their families again [12]. TB was common among students, as they lived in substandard conditions [5]. An estimated 150,000 Indigenous children were forced to attend residential schools across Canada between their establishment in the 1800s and the final closure of the schools in 1996 [12].

The legacy of residential schools is one of intergenerational trauma that has impacted not only those who were forced to attend and those who lost their children, but Indigenous people and communities today for whom the schools will never really close [10]. Children, more so than adults, were the focus of behaviour modification like the residential school system, because they were younger and could more easily be forced through lessons and punishments to forget what they knew, learn English and practice Anglophone Christian customs [11]. This erasure of traditional language and beliefs has raised generations of Indigenous people who felt alienated from their parents and families when they returned to their reserves [11]. Many were therefore driven by feelings of exclusion to move to urban settings where they lacked the resources and support they would need to thrive [11]. This alienation was coupled with a lack of opportunity to visit parents, or write them letters, almost completely cutting off these children from their community and support systems [12]. Unable to grow up surrounded by

their own culture, they were made to feel alone, caught between a reserve community they no longer knew and a mainstream culture they were still too different to be a part of. For many children of residential schools, now grown up and parents or grandparents themselves, this lack of a genuine cultural education from their community continues to impact them today, because they were not taught how to pass on their customs and language to their children [10]. Also, the enduring trauma of abuse and mistreatment has led to a mental health crisis amongst Indigenous communities [10]. High rates of suicide among young Indigenous people are exacerbated by the damaging impacts of substance abuse and poverty [12]. The legacy of residential schools threatens the very survival of both Indigenous people and their culture.

The story of TB in the Canadian North, like that of residential schools across the country, is one of ongoing trauma. Understanding this history is imperative in order to make genuine progress in combating TB. Up until the 1950s, TB rates amongst First Nation and Inuit people in Canada were comparable to those in developing countries [5]. This crisis led to a dramatic and cruel response on the part of the Canadian Government, wherein ships, such as the infamous C.D. Howe, were sent up to Indigenous communities in Northern Canada to screen people for TB [1]. Those who were sick or suspected to be infected were forcibly removed, marked with a "TB" on their hand and taken away [5]. They waited on the ship until it was ready to take those on board down south to be treated in sanatoria across the country [5]. These people were tested and taken without their consent and without the process being explained to them. Many of those forced to go were children, because young people are particularly susceptible to illness. This process continued the destruction of Indigenous culture by the residential schools, as more children and adults were forced to leave, treated by doctors who did not speak their language, prevented from reaching out to their families, and often dying without ever returning home [2]. There was a fundamental lack of genuine and intentional communication between Indigenous people and the Canadian Government. Thus, there is an enduring reluctance in Indigenous communities to undergo TB screening and to seek treatment, because this process has historically been associated with abuse and violence [2].

Moreover, residential schools, TB registries, and other regulation mechanisms like the 1876 Canadian Indian Act are examples of development as governmentality. This is a critical part of the modern disciplinary apparatus whereby the state controls their citizens' behaviour and attitudes to produce normal, moral, docile citizens who conform to the ideals of the state [13]. To act on this normative process, the state uses infrastructure and social institutions like schools, hospitals, and documentation such as passports [13]. Residential schools and the Indian Act have been critical tools of this governmentality, because they enforced the dichotomy between ideal Canadian citizens and the others. Furthermore, Canada has created a healthcare system that is tailored to meet only the needs of this normalised citizenry, while ignoring the aspects of Indigenous culture that do not fit within the boundaries of what is accepted. For example, most hospitals and hospital staff are unable to offer services in native Indigenous languages, and do not consider spiritual health or community healing as important aspects of healthcare delivery [14]. Wilmot [7] writes, "Where alien cultural values are imposed by the health care system, the cultural rights of indigenous service-users are compromised." He highlights how social services that do not engage a diversity of culture act to suppress

rather than support. Culturally appropriate care cannot be universal, and it will necessarily look different depending on the group of people it has been designed to serve [7].

These discriminatory actions exemplify the narratives of development thinkers like Harrison [15] who believe in cultural determinism; the idea that some cultures are more development prone than others because of the inherent characteristics that define them. Cultural determinist thinking in Canada has valued the Canadian culture; supposedly the reason for the economic growth of this country, and thus in the name of continued growth was committed to wiping out culture deemed antithetical. The cultural determinism narrative is one born largely of racism and feelings of superiority, and an assumption that people who are different are unable to succeed [15]. This narrative ignores the realities of inequity to justify exploitative practices in the name of development [15]. Cultural determinism labels those people who have had land and resources plundered and abused as just fundamentally backwards, and thus their suffering is not the fault of external actions but rather simply inherent in their culture [15]. Present-day developing countries and communities are mainly those that have experienced the violence, subjugation, and resource theft of colonisation at the hands of others. It is ignorant and hypocritical to blame a lack of development on the very people who countries like Canada have exploited to grow and become prosperous. The reality of first contact and the civilisation process is that Indigenous people around the world continue to exist among the lasting impacts of structures designed to exploit them, drive them out, or simply make them disappear. Indigenous persons in Canada are not less educated, driven, or capable, but rather they face more obstacles than the general Canadian public. Not only because of the enduring legacy of colonial violence, but because of structural inequalities that make day-to-day life more difficult [9]. Indigenous people in Canada struggle with accessing basic goods and services like housing and food, and are also less likely to secure a college degree and more likely to be stopped by police, arrested, and serve a prison sentence [9]. These are symptoms not of a second-class culture but of an unfair system; one that does not accept responsibility for, or take action against, historical and ongoing discrimination. Unequal colonial relations based on who has power and who does not continue to persist, regardless of how many years have passed since the settlers stopped being European immigrants and started being Canadian. This power imbalance is a driving force behind many active responses of Indigenous groups to unfair processes, especially in the fight for self-determination and self-governance.

The language and theories that support the idea of the end of colonialism devalue the real and genuine impacts that colonialism continues to have on lives today. They are part of the collective amnesia in Canada; the gradual forgetting of a public conscience unwilling to accept responsibility and confront its own actions [10]. Collective memory is the social construction of narratives and representations of the past, while collective forgetting silences these narratives and voices to create the normative dominance of one experience over another [16]. Memory can be manipulated, and made to represent only a fraction of the historical truth. While Indigenous people in Canada are forced by reality to continue to grapple with colonialism and its many facets of enduring suffering, the general Canadian public is able, and in fact encouraged, to move on and to forget. There is a lack of representation of Indigenous voices in

government, and in making the decisions that impact Indigenous lives and futures. This is particularly relevant in the health system, where there are few doctors, nurses, and support staff who are Indigenous themselves or who are taught to understand and work with Indigenous-specific needs [14].

Looking to the future, the Federal Government announced in 2018 that Canada will eliminate TB by 2030 [17]. The former Minister of Indigenous Services, Jane Philpott, acknowledged that curing TB will not only be about medicine but also about social support and development for Indigenous people [17]. The moral cost of allowing TB to remain a problem amongst Indigenous persons in Canada is apparent, and should be more important to Canadians than the potential economic and epidemiological benefits of eradicating TB in Canada [1]. In their article, *Tuberculosis in Nunavut: a century of failure*, the authors stress that gains will not be made in TB management until the Canadian Government is willing to work with local communities and support, rather than supplant, their efforts [2]. Given the legacy of pain and exclusion that Indigenous people in Canada have faced, it is imperative that screening and treatment campaigns be community driven and community focused. This is especially important given the traumatic history of TB management in the Canadian North. There is a fundamental sense of mistrust and a continued lack of two-way communication between major actors that threatens any eradication goals. As Faier [18] writes in her book about Filipina women in Japan, encounters and interactions between people are not random; they are overwhelmingly shaped by both history and power relations. Communities need to be supported with funding and resources and medical training, so that they are able to drive interventions. Leaders like Natan Obed, who is president of the ITK, the national representational organization for Canada's Inuit people, will be necessary partners alongside medical and government workers [19]. Furthermore, little progress will be made in TB management without sustained improvements in the social determinants of health, which are the structural, economic, and social conditions that impact health. Thus, there needs to be long-term investment into housing, job opportunities, water and sanitation systems, and education in Indigenous communities [2]. Czyzewski [10] considers colonialism itself, because of its undeniable impact on social and community suffering, to be a distal determinant of health. As such, not only do physical and economic improvements need to be made, but also ongoing efforts for reconciliation and the promotion of Indigenous culture [10].

Canadian colonial history is, in truth, more of an ongoing story. Indigenous people in Canada continue to be treated as second class, and the impacts of this inequality are striking in the health-care system. TB is a particularly apt point of inquiry, because like colonial practices, it should have been, and could have been, left in the past. Indigenous communities continue to suffer the consequences of TB predominantly because they continue to suffer the unfair and enduring consequences of colonialism. To separate TB, and more broadly health in general, from this legacy will prevent Canada from ever achieving a health landscape that reflects the development status and potential of this country. To push for a tomorrow that is representative of the Canada the world should know, there is a need for the government and the healthcare sector to understand the importance of culture and the cultural implications of Canada's history with Indigenous people. Turning a blind eye to the past will not serve to create a fair and just future, but

rather it will continue to drive the enduring legacy of TB, the White Plague, in Canada [3].

CONFLICTS OF INTEREST

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