Sanitoriums and the Canadian Colonial Legacy: The Untold Experiences of Tuberculosis Treatment

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Jessica Moffatt¹, Maria Mayan², and Richard Long²

Abstract

Sanitoriums served a much-needed purpose in the age prior to antituberculosis drugs: They removed the infected patient from wider society and created an environment that promoted recovery. We aimed to (a) describe sanitoriums from the perspective of a First Nations reserve community in northern Canada and (b) understand the impact of the sanitorium experience at a community level. Semistructured interviews (n = 15) were conducted in a First Nations reserve community with a high incidence of tuberculosis. Purposive and snowball sampling were used to obtain the sample. Data collection and analysis were iterative, using qualitative content analysis. Participants described the exclusion resulting within and because of sanitoriums. Exclusion within sanitoriums was categorized into (a) the exclusion of Aboriginal culture and practices of healing from the treatment of tuberculosis and (b) the internal exclusion, in which members of the community internally labeled the healed individual postsanitorium as an outsider.

Keywords

Aboriginal people, North America; community and public health; tuberculosis; relationships, patient-provider

A tragic experience Aboriginal people in Canada share is the effects of colonization. The term Aboriginal within the context of this study refers to First Nations, Inuit, and Métis people. Along with the fur trade came European colonizers and, subsequently, policies that promoted European ideals through a system of forced assimilation. Colonization brought with it the banning of many traditional practices and the erosion of families and communities, spiritual practices, and traditional ways of life (Kubik, Bourassa, & Hampton, 2009). Further to this, the colonial system brought with it policies of racial exclusion (Blackburn, 2009). For example, under the Indian Act of 1876, First Nations and Inuit people were legally considered wards of the state—allowing government to dictate most aspects of their life (Fiske, 1995). With the end goal of assimilation, this law authorized the transfer of many First Nation and Inuit children to residential schools to become "civilized," making it illegal for First Nations and Inuit peoples to own property, vote, or attend higher educational institutions.

Woolner (2009) argued that within the Canadian context, the lived experiences of Aboriginal Canadians have been excluded from the narrative of Canadian history. She referred to "collective amnesia," wherein society jointly ignores significant aspects of history, including the context of health. Within this study, we explored the stories of one First Nation community's experiences of

the sanitorium system, which were hospitals designed for the treatment of tuberculosis (TB). Although treatment was the same for Aboriginal and non-Aboriginal peoples, the Eurocentric model that sanitoriums were built upon might have been difficult and confusing for many Aboriginal patients. The purpose of the study was (a) to describe the sanitorium experience from the perspective of a First Nation reserve community in northern Canada and (b) to understand the impact of the sanitorium experience at a community level. To our knowledge, no academic literature exists documenting the experiences of First Nations peoples within sanitoriums.

Sanitoriums served a much-needed purpose in the decades preceding the availability of effective antituber-culosis drugs: They separated the infectious patients from healthy society and placed them in an environment designed to optimize their chance of cure. In the early 1900s, Aboriginal Canadians living on the prairies were 20 times more likely to die from TB than non-Aboriginal

¹Institute of Health Economics, Edmonton, Alberta, Canada ²University of Alberta, Edmonton, Alberta, Canada

Corresponding Author:

Jessica Moffatt, Department of Medicine & Faculty of Extension, University of Alberta, 8326 Aberhart Centre, Edmonton, Alberta, Canada, T6G 2J3.

Email: Moffatt2@ualberta.ca

Canadians (Sproule-Jones, 1996). Light was first shed on TB rates among Aboriginal Canadians in the early 20th Century when public health officials began to notice the number of First Nation and Inuit deaths occurring across Canada (Kelm, 2005; Sproule-Jones).

Within the context of TB, public health officials were granted the authority to coercively institutionalize the affected, forcibly removing infected individuals and placing them in sanitoriums (Shedden, 2011). Before the discovery of antituberculosis drugs, those suffering from TB were institutionalized in TB sanitoriums for a "rest cure," which was the dominant means of TB treatment at the time. Once admitted to the sanitorium, patients were often required to stay for extended periods of time—months, or even years. Treatment included rest, relaxation, emphasis on proper nutrition, and exposure to fresh air and sunshine. Sanitoriums also performed an important infection control purpose in that they removed the infectious individual from healthy society (Long, 2007).

Methods

Theoretical Framework

In this study, we utilized postcolonial theory. Getty (2010) stated that postcolonial theory

provides a lens through which to examine underlying issues of power and the structural and historical institutions that benefited from this domination . . . it provides a systematic way to examine how the historically situated social relations that have created oppression continue to structure the social location of oppressed people and to decide on the tangible conditions of their lives. (p. 7)

In alignment with the objectives defined by Macleod and Bhatia (2008), postcolonial theory helped us to (a) examine the Canadian history of colonialism, (b) produce culturally relevant research, and (c) produce knowledge that empowers the colonized peoples. By using a postcolonial theoretical framework, we were able to understand how knowledge generated within the participating community was shaped through the power relations of colonialism. Specific to TB, postcolonial theory allowed us to understand how colonialism played a role in participants' experiences of sanitoriums.

Ironically, one of the critiques of postcolonial theory is that it does not reflect Aboriginal ways of knowing (Getty, 2010). To ensure Aboriginal worldviews were the core of this project, we used a community-based participatory research (CBPR) approach to guide the study. Recognizing the inequalities tied to health, such as poverty, racism, and powerlessness, it was clear that researchers must consider a contextual ecological perspective, one that considers the social inequalities that

shape our health (Israel, Schulz, Parker, & Becker, 1998). Central to CBPR is the emphasis on the participation of community-based researchers, as opposed to participation of only academic researchers, who are actively engaged in all aspects of the research process (Israel et al.; Jacklin & Kinoshameg, 2008). Through this partnership we were able to understand the issue on a much deeper level. As such, a CBPR approach helped us to align with the Canadian Institute of Health Research's "Guideline for Research Involving Aboriginal Peoples" (2007), which states that Aboriginal people should be given the option of a participatory approach to research. Unsurprisingly, a CBPR approach is increasingly utilized for research partnerships among many Aboriginal communities across North America (Furgal & Seguin, 2006; Petrucka, Bassendowski, & Bourassa, 2007; Worthington et al., 2010).

Ethics and Community Advisory Boards

This study was approved by the Research Ethics Board at the University of Alberta. The project was initially presented to the community chief and council for approval. Through this meeting, concerns over community intellectual property, participant anonymity, and the overall benefits to the community were addressed. In addition to this meeting, the research team met regularly with the director of health at the community's health center to provide project updates.

Furthermore, a community advisory board (CAB) was constructed to ensure that the project upheld the guidelines outlined by chief and council. The CAB constituted nine community members (Elders, health care staff, and lay community members) and met at various points throughout the project. One of the main purposes of the CAB was to ensure that the cultural values of the community were respected and that the project moved forward in a culturally sensitive manner. In addition to the CAB, two coinvestigators were recruited from the community to work as partners with the first author. The coinvestigators were both champions for health in their community and were interested in gaining research skills and knowledge. Those involved in the project—the CAB members, the coinvestigators, and the first author formed an equitable partnership, with each member bringing unique and valuable insights to the project.

Data Collection and Analysis

The project was introduced to the larger community at the annual Community Health Day. The research team presented an overview of the project, which was followed by a community barbeque. At this gathering, community members were told where they could obtain more

information if they were interested in participating in the project. Purposive and snowball sampling was used to obtain the study sample. Using this sampling technique allowed us to target participants with some experience of TB. Inclusion criteria included any community member older than 14 years who had personally or through a family member experienced TB disease.

Data were collected through 15 semistructured interviews, with three follow-up interviews. The 15 initial interviews were conducted by the first author and the coinvestigators, whereas the three follow-up interviews were conducted solely by the first author. After discussion with the coinvestigators, we decided that three of the original interviews were superficial and that more information could be gathered through follow-up interviews with these individuals. Together, we decided the first author would conduct the follow-up interviews independently, with a hypothesis that as an outsider these individuals might feel more comfortable talking to her alone. The sample included 11 women and 4 men, all members of the same participating First Nation reserve. Of this sample, 7 participants had spent time in a sanitorium, 3 had a family member institutionalized in a sanitorium, 1 participant had been treated for TB in an outpatient setting, and 4 participants had both spent time in a sanitorium and had a family member institutionalized in a sanitorium. Participants ranged in age from 19 to 63 years.

Interviews were conducted by either one of the coinvestigators or the first author, occurring either at the community health center or at the participant's home. Each interview lasted approximately 1 hour. Participants were initially asked questions about their general knowledge of TB, later moving to questions about personal experiences with TB. Community protocols, such as presenting tobacco when meeting with an Elder, were followed during all interviews to respect cultural values and to maintain rapport with participants.

With consent, interviews were audio recorded and transcribed verbatim by a non-Aboriginal transcriptionist not involved with the study. Data were checked by the first author against the original audio tapes to ensure accuracy. Data collection and analysis were iteratively conducted by the first author, using qualitative content analysis until saturation was reached; that is, until the coding process became redundant and nothing new was being contributed to the categories. Transcripts were analyzed line by line and codes important to the project objectives were identified. This coding process occurred concurrently throughout the project. As each new interview was conducted, the transcript was immediately included in the coding process and the interview guideline was altered to reflect any new codes resulting from the previous interviews. Shkedi (2005) highlighted the importance of ensuring that the categorization process is

empirically grounded and internally sound. Therefore, codes were initially identified by the first author, verified through weekly meetings with the coinvestigators, and presented to the CAB and community health staff outside the core research team to ensure cultural relevancy.

Rigor/Trustworthiness

To ensure that the project was rooted in rigor/trustworthiness, a number of steps were taken throughout the project. To ensure credibility, the first author spent prolonged time (more than 1 year) in the community prior to data collection. Additionally, the data were checked with members of the project on an ongoing basis. Once a week, data were presented by the first author to the coinvestigators to assess if the analysis was representative of the interviews and stories heard through these interviews. Data were also presented to the CAB at two points during the project—once approximately half-way through data collection and once when the coinvestigators and the first author believed saturation had been reached. To ensure dependability, substantial time was dedicated to creating a strong audit trail. For example, while driving back from the community, the first author would audio record a personal discussion of her reflections on the day, talking aloud about what she had observed or the experiences that had been shared with her in the interviews. The first author would also memo in a journal once back at her office at the University, to document reactions and emotions, which additionally strengthened the audit trail as well as achieve confirmability. Additionally, final data were presented to the CAB to verify key themes expressed in the data.

Finally, to ensure transferability, when possible, a thick description of the research setting was provided. We should note that the ability to provide a thick description of the community had to be balanced with the apprehensiveness community members felt about being identified as a high-incidence community. This likely speaks to the intense stigma still surrounding TB throughout the reserve. On many occasions throughout the project community members expressed their concern that the project would identify the community, and therefore we had to continually provide reassurance that they would not be identified. Recognizing that this might limit transferability, we believe (as would any ethics board) that it was imperative to honor this wish, and as such have excluded any details that could identify the community.

Dissemination of Findings

An important piece of this research was the construction of a community-owned educational video for the purpose of disseminating the stories and experiences shared with us throughout the project. Waisbord (2007) argued that the communication of the TB message is an important component to understanding and addressing TB. The author suggested that the message being communicated should be sensitive to the unique experiences of the audience and should include both sociocultural and health components. In alignment with Waisbord, we decided the video would be based on the findings of the study, would address both sociocultural and biomedical components of the disease, and would be unique to the participating community.

The concept of the video was considered for two reasons. First, we recognized that one of the goals of a CBPR approach is to highlight social inequities and spark social change (Israel et al., 1998). After preliminary discussions with the CAB, it was apparent that the topic of TB was not something openly discussed within the community because the topic was heavily stigmatized. We understood that before social change can occur, the stories and experiences of community members must be formally recognized and shared (Burgess, 2006; Jacklin & Kinoshameg, 2008). Through a video, the community was formally presented with a platform to document their personal experiences with TB.

Second, CBPR researchers often discuss the importance of project sustainability, meaning the project benefits should persist long after the academic researchers are no longer working within the community (Minkler, 2005; Minkler, Brenckwich Vasquex, Rains Warner, Steussey, & Facente, 2006). The video helped us create an ideal format to educate community members and could be used as a sustainable tool long after we left the community. It was decided the video would be owned solely by the health center, rather than co-ownership between the community and the university, meaning the community could utilize the video in the future however they saw fit.

In keeping with the core values of CBPR (Jacklin & Kinoshameg, 2008), we contracted a community-based production company that was recommended by the chief and council to help us produce the video. Two perspectives were presented within the 20-minute video. We wanted to document experiences with the sanitorium system, and we wanted to provide education on the biomedical aspects of TB, including the symptoms, stages, treatment options, and the importance of taking anti-TB medication.

Findings

Using a postcolonial lens helped us examine the power differentials that shaped many of the experiences described by participants. The results were grouped into experiences within sanitoriums, experiences returning from sanitoriums, and effects of sanitoriums on present-day health behaviors.

Experiences in Sanitoriums

The act of being removed from the community, once diagnosed with TB, was described as a traumatic event. Many participants did not understand the disease and therefore did not understand why they were being confined to a sanitorium. Hence, being removed from the community was surrounded by confusion, and had lasting effects on the individual. As one participant described, "Being lifted from home and taken away without explanation really made an imprint on my mind, and it was never, never talked about. It was never clarified."

Participants discussed the isolation they experienced and the individualistic nature of their treatment once admitted to the sanitorium. Traditional healing activities such as smudging, healing circles, or other group healing practices were not permitted within the sanitorium. Participants spoke of the predominantly White medical staff working at the sanitoriums. Medical staff were often described as unfriendly and thought of as "people who didn't have any knowledge of our culture"; however, other inpatients were described in a more positive light. In fact, many life-long friendships were forged within the walls of the sanitorium. As one participant described, "I met a lot of friends there. I even met a girl there. I used to chum around with her, and she was my best friend. She had TB too."

Experiences Returning From Sanitoriums

The time an individual spent in the sanitorium had lasting impacts when he or she returned to the community. Once returning home, the TB health workers were still a constant presence within their lives. One participant explained:

They were called health workers. They came from some government office. They said, "You people are dirty; that's why you have TB." I still remember the health worker's name, because my mom would say, "The TB health worker is coming and I want you guys to go wash your face and make sure you are clean." Mid-day she would call us in and tell us to wash up and be ready for the TB health worker.

Since the sanitorium system required sick individuals to be removed from the community for long periods of time—months, and sometimes years—disconnect was created between the community and the individuals. When healed individuals returned from the sanitoriums, many aspects of their culture were forgotten. One participant described her first day returning to her family:

When I got back from the sanitorium, everyone was happy to see me so we had a feast. My mom put the table cloth out and it was like a picnic every day for us because we didn't have tables. We just had the tablecloth on the floor and everybody

sat around it. Everybody was sitting down to eat. Everybody was passing around the food and, just like a celebration, they are sitting down. Everybody was laughing, and here I am just quietly walking around, looking at everybody. My mom stopped and says, "What's the matter, babe? Aren't you going to sit down and eat with us?" I just looked at everybody, and I said, "Do I have to sit down like an Indian?" Everybody laughed at the time, but they didn't realize that I came back from the sanitorium with different ideas.

Similar to a loss of culture, participants highlighted the loss of language that resulted through sanitorium experiences. English was the dominant language spoken within the walls of the sanitorium, and as most of the health care staff were non-Aboriginal, long periods of time were spent communicating in English. Participants described entering the sanitoriums fluent in their language, yet returning to the community unable to speak their mother tongue:

When I was there, I had a good grasp of the English language and I spoke English fluently. When I came back into my community, I spoke not one word of my own language and I couldn't remember how to speak it. I haven't spoken it for many years and it's only now just coming back to me.

When I was in the sanitorium, I lost my language. I came back to the community and I was fluent in English. My parents always told me this story of the first day I came back. They thought it was so funny. They didn't understand that it affected me deeply that I lost my language.

The loss of language meant some participants were unable to communicate with family members and other loved ones on returning home:

When my brother returned from the sanitorium, he only spoke English and we spoke our traditional language. We had a communication barrier. But my grandfathers and my grandmothers, they put us together and told us that we were separated, but not in blood.

Participants also described the disruption that occurred by the removal of a family member into the sanitorium. Having a loved one absent for long periods of time eroded the sense of family. Sanitoriums were seen as institutions that were extremely disruptive to families:

My brother went to the sanitorium and stayed there for seven years because he was allergic to the medication. It took seven years for the tuberculosis to go dormant. I never knew my brother. My older sister has no memory of him. My siblings never met their brother until he was thirteen. He was a total stranger. That's the emotional part—that we had a brother we never knew.

When a parent was institutionalized, this caused massive disruption to the family. One participant described

being a little girl and having her mother institutionalized in a sanitorium:

One day my auntie told me that my mom had collapsed at work and they had to take her to the hospital. We [couldn't visit her for] about three months I think. It was just before Christmas when we finally saw her again. There were eleven of us siblings. I'm the fourth oldest and we were home by ourselves. My older sisters tried to take care of us, but they were teenagers. One day Social Services came and split us all up. There was so many of us they couldn't keep us in one house, so we were separated into different homes. My sisters, we all ended up in a home in the city. Another two of my siblings were just next door and were being fostered there. I didn't know what had happened to my younger brothers and sisters. Three of them had ended up with one of my aunties. We never saw each other all the whole time my mom was in the sanitorium. I remember riding on the bus and seeing them playing on the road in the mud. I couldn't even get off to go see them. During that time my dad wasn't around, because he was staying near the hospital so he could visit her. We never got a chance . . . nobody ever came to pick us up, bring her to visit or anything like that. Both my mom and my dad were gone.

When the healed individuals returned to their communities, some had not met other members of their family. As one participant described it, "Life on the reserve must go on." While sick individuals were in the sanitorium, families had babies, deaths occurred, and life continued. Participants described the time and effort it took to rebond as a family:

So anyways, we ended up becoming the brothers and sisters we were supposed to be but it didn't happen overnight. It was heartbreaking for our parents to see their kids were miles apart. I didn't know my older sister. My younger siblings had no memory of my older sister because they weren't even born yet.

A common thought expressed by participants was the idea that those returning from sanitoriums returned with pale skin:

It was a very tough situation for the family because, we as siblings rejected him because he looked like a White kid. He looked like a White kid because he was in a hospital with no sunshine. He was really white . . . Socially he became outcasted and ridiculed. The other kids called him "snowman" because he was so white. He was so white. I can't explain how white he was.

Further to the idea of returning with paler skin, participants also spoke of the weight gain associated with sanitoriums. Being overweight was extremely rare in the participants' community. As one participant explained, returning from the sanitorium with added body weight often subjected them to further ridicule:

When my brother got back from the sanitorium we called him "Bunny." He reminded us of a little, chubby, furry rabbit. That's what he reminded us of, I guess, a white bunny. He was so chubby, and looked so white. We'd never seen chubby people when we were kids.

Children were quick to bully other children returning from the sanitorium. One participant shared,

When my brother returned from the sanitorium, it was socially isolating for him. People poked fun of him because you didn't see people like that. When we started school, everybody called him fat and they'd run after him and they'd push him and he would fall. At the end result, he got hurt in the knee. He had a hairline fracture that bothered him for years.

The impact of such body changes affected participants throughout their lifetime. For example, one participant described returning to the community as a young girl after gaining weight in the sanitorium:

It took me a long time to get past the sanitorium experience because I was kind of withdrawn. I was a withdrawn child and I was not an outgoing person. I think I was withdrawn because of the experiences I had in the sanatorium. I was the heaviest in our family.

Effects of Sanitoriums on Present-Day Health Behavior

Participants described their fear of the disease returning, something that caused them to "walk on eggshells" once they left the sanitorium. This fear was felt by both the patient and his or her family, as explained by two participants:

When I got back to the community, my family was scared that something would happen to me, that the TB would come back. I was kind of just held back and told, "No don't do that, you might get sick again."

There was a time if I ever got a cold, or anything like that, I was worried the TB was back. I was petrified I'd have to go back. Back to the sanitorium. What if I still have it, or catch it again? I don't want to go back.

Because of the fear that the TB was back, many participants described their reluctance to seek medical care. To avoid becoming sick and having to seek medical care, preventive health behaviors were adopted:

You know, ever since the trauma of being away for so long, I have learned to look after myself. I've learned to eat right to make sure I don't go back to the sanitorium. . . . When you go through a whole year like that institution, kind of

unfriendly, you don't want to go back there again. Now I take care of my health personally.

The historical experiences of sanitoriums were still very much alive to participants and affected treatment behaviors and illness beliefs. Participants stated a belief that present-day health care would be similar to the treatments they received within the sanitoriums. An example of this was when participants discussed medication, because they felt doctors were only interested in prescribing medications:

Every time I see a doctor, just like the TB pill, all they want to do is give you pills. I don't like taking pills. I'd rather use herb medicine. I had to take the TB pills because I wanted to get better, but they used to make me sick all the time.

Because of the belief that treatment options today are similar to those available during their time in the sanitoriums, participants commented on the lingering impact of the sanitorium experience, saying things like, "The only time I go see a doctor is when I am really sick." Health care was something to be feared, rather than something that could heal.

Discussion

Prior to the availability of TB medication, patients were treated in sanitoriums. Lux (2010) argued that researchers must consider hospital systems as a residual byproduct of colonialism, something that has bred racial exclusion and segregation. The foundations of the sanitorium system were constructed under the premise of healing; however, the Eurocentric manner in which healing occurred was especially distressing for Aboriginal patients. Through a postcolonial lens we were able to identify the underlying power imbalance apparent within the sanitorium system, which was predominantly based on the exclusion of Aboriginal epistemologies. The exclusion experiences among participants in this study included (a) the exclusion of Aboriginal culture and practices of healing within the treatment of TB and (b) internal exclusion, wherein members of the community labeled the healed individual postsanitorium as "other."

Exclusion was promoted through the lack of Aboriginal ways of knowing within TB treatment, which was likely a reflection of the lack of cultural competency apparent during this time period. It has long been argued that the medical system, including public health, is an arm of the colonial system (Kelm, 2004; Shroff, 2011), one that exerts power and authority over those needing healing (Twohig, 1996). The very act of healing, something that was traditionally based on communality and connection to the community among many First Nations cultures (Winnipeg Regional Health Authority, 2009), was replaced

by an Eurocentric approach based on individualistic and biomedical healing. Participants spoke of the isolation and depression that resulted and described treatment as something to "get through" rather than a healing process. Traditional indigenous healing, although extremely diverse among populations, almost exclusively focuses on returning sick individuals to a state of balance—balance within themselves, their families, and their community (Shroff).

One of the central ways exclusion of Aboriginal ways of knowing was promoted through sanitoriums is through the use of language. Within the walls of the sanitoriums, English was the dominant language spoken; children were taught an English curriculum in the sanitorium schools, and patients interacted with the majority of other patients in English. Again, this could speak to the lack of cultural competency during this time period, but likely was also connected to the insufficient number of Aboriginal health care workers employed in this era. As a result, a major theme in participant's stories was the loss of language resulting through their time spent in sanitoriums. Without the ability to speak their mother tongue, participants, especially those spending numerous years healing in sanitoriums, lost the understanding of their language.

The use of language, specifically through Englishonly institutions, was an important tool in the colonial process, one that enforced power and social hierarchy (Knowlton, 2008). The link between language, power, and health is well documented within the literature (Maffi, 2001; McAlpine, Eriks-Brophy, & Crago, 1996; Mohanty, 2000). In a 2008 paper written for the United Nations Permanent Forum on Indigenous Issues, the enforcement of Aboriginal individuals into English-only speaking institutions was linked to "serious mental harm, social dislocation, psychological, cognitive, linguistic and educational harm, and, particularly through this, also economics, social and political marginalization" (Baer, Dunbar, Skutnabb-Kangas, & Magga, 2008, p. 1). Further, Norton (1997) argued that language is a key component to both cultural and social identity. Cultural identity was defined as the relationships between the individual and other members of their group who share common histories, languages, and ideologies. Social identity was defined as the relationships between the individual and the larger society (Norton). Participants explained the loss of cultural identity on returning home from the sanitoriums. They could no longer communicate with their family members and their community, and felt like outsiders.

Additionally, participants described returning from the sanitorium looking White, returning to the community looking paler and having gained weight, and explained the rejection that resulted. Once returning home, their appearance was noticeably different from their fellow community members. They were once again branded as outsiders and expressed feelings of disconnect from their culture. This is especially concerning, as disconnect from one's culture has been linked to higher rates of suicide, violence, depression, and addictive behaviors (Kirmayer, Brass, & Tair, 2000). The pathway between internal cultural exclusion and TB has not been addressed, suggesting the need for further research into this topic.

The effect of the historical sanitorium experience was very much alive in present-day behaviors, influencing how and when participants chose to interact with the current health system (Macdonald, Rigillo, & Brassard, 2010). Similar to other arms of colonization—for example, the residential school system in Canada—sanitoriums bred an atmosphere of distrust and exclusion. This distrust has been passed down through the generations, influencing present-day behavior of both those patients who had firsthand experiences with sanitoriums and the generations born after the sanitoriums closed their doors to TB patients. When asked about their feelings of today's health care system, participants spoke of a fear of having to return to the sanitorium and a fear of forced confinement. Such fears have led to a general mistrust of the health care system, which can have obvious and profound implications for TB control. Through a fear of TB control, we could expect to see very negative consequences, such as delayed diagnosis, poor rates of compliancy, and poor treatment outcomes.

Mistrust is a compounding, complex phenomenon, which has been built layer by layer as First Nations historically and continually experience instances of exclusion and discrimination. The sanitorium system is not solely responsible for the mistrust apparent within this study; however, TB control was, and still is, based on a power imbalance in which public health officials have the authority and mandate to protect others from infectious diseases such as TB. We do not suggest this authority is unnecessary; however, the importance of cultural sensitivity in future TB control efforts is indicated by the results of this study. Current TB control efforts should acknowledge the historical traumas many First Nations peoples experienced through the sanitorium system and how these experiences might influence present-day behaviors.

Public health officials working in TB control must adopt a culturally congruent approach to care, and acknowledge the traumatic experiences First Nations peoples have encountered at the hands of public health. Macdonald et al. (2010) suggested that health professionals must act with professional kindness when dealing with TB control among Aboriginal patients, which includes acknowledging the structural violence Aboriginal Canadians have experienced and the role TB

control has played in perpetuating this violence. This is further echoed by the works of Waisbord (2007), who suggested that TB control officials must look beyond the epidemiology, compliancy rates, and treatment outcomes to include the social conditions and past experiences of the disease that might be influencing patient health care decisions.

Conclusion

Through this study, we were able to document one First Nation community's historical experience with the sanitorium system. The prominent role public health officials working in TB control must adopt, to not only provide culturally congruent care but also acknowledge past traumatic experiences, was highlighted within the findings. Through documentation of the sanitorium system, light was shed on a significant yet silent part of Canadian colonial history.

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References

- Baer, L. A., Dunbar, R., Skutnabb-Kangas, T., & Magga, O. H. (2008). Forms of education of Indigenous children as crimes against humanity? New York: United Nations Permanent Forum on Indigenous Issues.
- Blackburn, C. (2009). Differentiating indigenous citizenship: Seeking multiplicity in right, identity, and sovereignty in Canada. *American Ethnologist*, *36*, 66–78.
- Burgess, J. (2006). Participatory action research: Perspectives of a graduate student. *Action Research*, *4*, 419–437.
- Canadian Institute of Health Research. (2007). CIHR Guidelines for Health Research Involving Aboriginal Peoples. *Canadian Institute of Health Research*. Retrieved from www.cihr-irsc.gc.ca/e/29134.html
- Fiske, J. A. (1995). Political status of Native Indian women: Contradictory implications of Canadian state policy. *American Indian Culture and Research Journal*, 19, 1–30.

- Furgal, C., & Seguin, J. (2006). Climate change, health, and vulnerability in Canadian northern Aboriginal communities. *Environmental Health Perspectives*, 114, 1964–1970. doi:10.1289/ehp.8433
- Getty, G. A. (2010). The journey between Western and Indigenous research paradigms. *Journal of Transcultural Nursing*, *21*, 5–14. doi:10.1177/1043659609349062
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202. doi:10.1146/ annurev.publhealth.19.1.173
- Jacklin, K., & Kinoshameg, P. (2008). Developing a participatory Aboriginal health research project: Only if it is going to mean something. *Journal of Empirical Research on Human Research Ethic*, 3, 53–67. doi:10.1525/jer.2008.3.2.53
- Kelm, M. E. (2004). Wilp Wa'ums: Colonial encounter, decolonization and medical care among the Nisga'a. Social Science & Medicine, 59, 335–349.
- Kelm, M. E. (2005). Diagnosing the discursive Indian: Medicine, gender, and the "dying race". *Ethnohistory*, 52, 371–406.
- Kirmayer, L., Brass, G. M., & Tair, C. (2000). The mental health of Aboriginal peoples: Transformations of identity and culture. *Canadian Journal of Psychology*, 45, 607–616.
- Knowlton, T. (2008). Dynamics of Indigenous language ideologies in the colonial redaction of a Yucatec Maya cosmological text. *Anthropological Linguistics*, 50, 90–112.
- Kubik, W., Bourassa, C., & Hampton, M. (2009). Stolen sisters, second class citizens, poor health: The legacy of colonization in Canada. *Humanity & Society*, 33, 18–34.
- Long, R. (2007). The Canadian Lung Association/Canadian Thoracic Society and tuberculosis prevention and control. Canadian Respiratory Journal, 14, 427–431.
- Lux, M. K. (2010). Care for the "racially careless": Indian hospitals in the Canadian west, 1920-1950s. *Canadian Historical Review*, 19, 407–434.
- Macdonald, M. E., Rigillo, N., & Brassard, P. (2010). Urban Aboriginals' understanding and experiences of tuberculosis in Montreal, Quebec, Canada. *Qualitative Health Research*, 20, 506–523. doi:10.1177/1049732309360538
- Macleod, C., & Bhatia, S. (2008). Postcolonialism and psychology. In C. Willig & W. Stainton Rogers (Eds.), The SAGE handbook of qualitative research in psychology. London: Sage.
- Maffi, L. (2001). Biocultural diversity: Linking language, knowledge, and the environment. Washington, DC: Smithsonian Institute Press.
- McAlpine, L., Eriks-Brophy, A., & Crago, M. (1996). Teaching beliefs in Mohawk classrooms: Issues of language and culture. *Anthropology & Education Quarterly*, 27, 390–413.
- Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health*, 82, ii3–ii12. doi:10.1093/jurban/jti034
- Minkler, M., Brenckwich Vasquex, V., Rains Warner, J., Steussey, H., & Facente, S. (2006). Sowing the seeds for sustainable change: A community-based participatory research partnership for health promotion in Indiana, USA

and its aftermath. *Health Promotion International*, 21, 293–300. doi:10.1093/heapro/dal025

- Mohanty, A. K. (2000). Perpetuating inequality: The disadvantage of language, minority mother tongues, and related issues. In A. K. Mohanty & G. Misra (Eds.), *Psychology of poverty and disadvantage*. New Delhi, India: Concept.
- Norton, B. (1997). Teachers of English to speakers of other languages. *TESOL Quarterly*, 31, 409–429.
- Petrucka, P., Bassendowski, S., & Bourassa, C. (2007). Seeking paths to culturally competent health care: Lessons from two Saskatchewan Aboriginal communities. *Canadian Journal of Nursing Research*, 39, 166–182.
- Shedden, D. (2011). Public Health Agency of Canada, presentations: TB in Aboriginal people in Canada (Medical Service Branch). Ottawa, ON, Canada: Public Health Agency of Canada.
- Shkedi, A. (2005). *Multiple case narrative: A qualitative approach to studying multiple populations*. Philadelphia: John Benjamins.
- Shroff, F. M. (2011). Power, politics, and the takeover of holistic health in North America: An exploratory historical analysis. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 9, 129–152.
- Sproule-Jones, M. (1996). Crusading for the forgotten: Dr. Peter Bryce, public health and prairie native residential schools. *Canadian Bulletin of Medical History*, *13*, 199–224.
- Twohig, P. T. (1996). Colonial care: Medical attendance among the Mi'kmaq in Nova Scotia. *Canadian Bulletin of Medical History*, *13*, 33–53.

- Waisbord, S. (2007). Beyond the medical-information model: Recasting the role of communication and tuberculosis control. Social Science & Medicine, 65, 2130–2134.
- Winnipeg Regional Health Authority. (2009). The culture of wellbeing. Winnipeg Regional Health Authority. Retrieved from www.cmhawpg.mb.ca/documents/TheCultureof WellBeing2009-2ndEdition.pdf
- Woolner, C. (2009). Re-storying Canada's past: A case study in the significance of narratives in healing intractable conflict (Unpublished doctoral dissertation). University of Notre Dame, Notre Dame, Indiana.
- Worthington, C., Jackson, R., Mill, J., Prentice, T., Myers, T., & Sommerfeldt, S. (2010). HIV testing experiences of Aboriginal youth in Canada: Service implications. *AIDS Care*, 22, 1269–1276. doi:10.1080/09540121003692201

Author Biographies

Jessica Moffatt, PhD, is a research associate at the Institute of Health Economics, Edmonton, Alberta, Canada.

Maria Mayan, PhD, is the assistant director of the Community-University Partnership at the University of Alberta, Edmonton, Alberta, Canada.

Richard Long, MD, is a professor in the Department of Medicine at the University of Alberta, Edmonton, Alberta, Canada.