The Value of Connections for Aboriginal Peoples Navigating the Tuberculosis Experience

by

Tristan Robinson

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Department of Human Ecology
University of Alberta

ABSTRACT

Throughout the twentieth century, tuberculosis (TB) was and continues to be a pressing health problem facing Canadians. Aboriginal peoples living in Canada carry a large burden of the disease with those living in the Prairie Provinces facing TB rates consistently higher than the national average. Tuberculosis affects Aboriginal peoples and their communities differently, while some reserves have been left relatively untouched, others face TB rates which are exceptionally higher than the national average. Currently, researchers have been trying to understand why TB continues to impact Aboriginal peoples in Canada. The research has largely been conducted on the historical trauma that Aboriginal peoples faced when being treated for TB, as well as on the socioeconomic disparities that increase the spread of the disease. The central purpose of this study was to understand the TB experience for Aboriginal peoples living in different community settings across the Prairie Provinces, from experiencing symptoms, to seeking a diagnosis, to being treated. This study used secondary qualitative data from a larger research project. Interviews from 48 Aboriginal participants who lived in urban centres and on non-remote, remote, and isolated reserves in Alberta, Saskatchewan, and Manitoba were used to answer the research question. The interviews were analyzed using qualitative content analysis. Four prominent themes emerged which impacted the TB experience including the role of the individual, the impact of social connections, the impact of community, and the impact of isolation policies. Within each theme there were many sub-themes that highlighted important similarities and differences that Aboriginal peoples from various community settings experience when living and being diagnosed with TB. The findings highlight the value of connections in the lives of Aboriginal peoples experiencing TB. Not all individuals are equally connected to a source of support that could improve their overall TB experience therefore, there is a need to

improve current TB policy and practice for Aboriginal peoples living both in urban centres and on-reserve.

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CHAPTER 1: INTRODUCTION

Throughout the twentieth century, tuberculosis (TB) was a major cause of mortality and was considered the most pressing health problem facing Canadians (Canadian Public Health Association, 2009; Public Health Agency of Canada, 2009; Wilkins, 1996). Tuberculosis is caused by bacteria, which most commonly affect the lungs, spread from person to person through the air. When the individual does not have a strong immune system, the bacteria grow and become active TB (World Health Organization, 2014). Due to the airborne nature of the disease, TB is highly contagious, spreads rapidly, and has affected many individuals throughout the country (Health Canada, 2012). At the peak of its epidemic (late 1800s), TB mortality was 200 per 100,000 Canadians. In the latter half of the twentieth century, with improvements in living conditions and drug treatments, TB rates began to rapidly decline (Public Health Agency of Canada, 2009). However, despite advances in TB treatment, impoverished populations in Canada (e.g., homeless, Aboriginal peoples, immigrants) continue to be affected by the disease (Health Canada, 2009; Public Health Agency of Canada, 2009).

In the early 1900s, Aboriginal[1] peoples who lived in the Prairie Provinces (Alberta, Saskatchewan and Manitoba) were found to be 20 times more likely to die from TB (Sproule-Jones, 1996). Current national trends show that the Prairie Provinces have consistently documented higher TB rates than the national average (4.8 per 100,000 in 2012) with Alberta, Saskatchewan, and Manitoba at 5.1, 8.4, and 10.8 per 100,000, respectively (Public Health

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[1] The term Aboriginal will be used to refer to Métis, Inuit, Treaty First Nations, and non-Treaty First Nations, living both on and off-reserves (Aboriginal Affairs and Northern Development Canada, 2013). A large portion of Aboriginal communities and people share similar experiences in their history of colonization, reserve living, residential schools, and face disadvantages due to government imposed policies (Health Canada, 2012).

Agency of Canada, 2013). Aboriginal peoples[2] and their communities continue to be disproportionately affected by these high TB rates. Although they represent approximately 5% of the Canadian population yet, Aboriginal peoples compromise over 50% of the active TB cases in the country (Long et al., 2013; Statistics Canada, 1992; Waldram, Herring, & Young, 2006). Compounding the issue of high TB rates, Aboriginal peoples living in the Prairie Provinces have the most advanced presentations of TB infection (Health Canada, 2009).

Rates of TB amongst Aboriginal peoples vary greatly across provinces and community settings. While the disease has devastated some Aboriginal communities, others remain comparatively untouched (Daschuk, Hackett, & MacNeil, 2006). Aboriginal peoples in Canada live in various community settings including urban centres and reserves[3]. The urban Aboriginal population is growing at a fast rate while, at the same time, many Aboriginal peoples continue to live on reserves across the country. Every urban centre and reserve is unique in its history, cultural identity, population, resources, and health services. Kaspar (2014) notes that the community is one of the most under-addressed ecological influences that affect health determinants for Aboriginal peoples. With the disparities in TB rates across the country, it is important to understand the experience of Aboriginal peoples living with TB across diverse communities. This study addresses this through the following research question: *What is the TB experience for Aboriginal peoples living in different community settings across the Prairie*

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[2] Aboriginal peoples are often treated as a homogeneous group, which is a large misconception. Each Aboriginal community has their own culture, traditions, and specific history (Voyageur & Calliou, 2000/2001). Additionally, each Aboriginal group and reserve has varied access to education, health and social services, housing, roads and basic infrastructure. However, for the purpose of this study the term Aboriginal peoples will be used for the sake of simplicity.

[3] A reserve in Canada is defined as a tract of land that was set up for Aboriginal peoples by the *Indian Act* and subsequent treaty agreements. Aboriginal peoples have exclusive rights to live on and use the land and services allotted to the reserve.

Provinces? In this study, the term “TB experience” is used to capture the entirety of an individual’s experience from first becoming infected with TB, acknowledging symptoms, accessing health services[4] seeking a diagnosis, to treatment.

There is no shortage of literature that highlights the vulnerable health conditions that many Aboriginal peoples are experiencing in Canada today. Indeed, the majority of research draws attention to the fact that the life expectancy of Aboriginal peoples is seven years shorter, their infant mortality rates are 40% higher, and their morbidity and mortality rates are significantly higher than non-Aboriginal Canadians (Frolich, Ross, & Richmond, 2005; Indian and Northern Affairs Canada, 2004; Kirmayer et al., 2007). These daunting health rates have been linked to the health and socio-economic inequities Aboriginal peoples face, including poverty, unemployment, low high school graduation rates, addiction issues, suicide, physical and sexual abuse, poor and overcrowded housing, lack of food security, and limited access to health services (Health Canada, 2012; Loppie Reading & Wien, 2009; Place, 2012; Trumper, 2004).

According to Browne, McDonald and Elliott (2009), one of the root causes of the poor distal[5] and intermediate[6] determinants of health Aboriginal peoples face today is the underfunding of important resources and services (e.g., education, health). Research has shown that Aboriginal peoples live in overcrowded and poor quality housing caused by a lack of investment in building homes on reserves. They face food security issues caused by the high cost of transportation to some remote and isolated communities. Programs such as Aboriginal Head

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[4] Health services includes all services dealing with the diagnosis and treatment of a disease as well as the promotion and maintenance of health (World Health Organization, 2015).

[5] Background factors that predispose people to greater or lesser health risks (Krieger, 2008).

[6] Can serve as intervening variables that mitigate the potential impact of distal factors (Krieger, 2008).

Start on-reserve are funded at a lower rate than for non-reserve Head Start programs. Finally, health services offered to Aboriginal peoples is largely underfunded and relies on a piecemeal approach to the delivery of care where ambiguous jurisdictional authority of service providers are required to meet the needs of the communities[7] (Loppie Reading & Wien, 2009). Aboriginal peoples living in urban centres and on-reserve have identified that access to adequate, competent, and culturally sensitive services is limited (Public Health Agency of Canada, 2013). Further to this, research has shown that when Aboriginal peoples do access health services they feel discriminated against and ignored by medical professionals, which deters them from utilizing hospitals and walk-in clinics in the future (Adelson, 2005; Browne, 2005; Place, 2012). These health and socio-economic disparities that Aboriginal peoples and their communities face are directly related to elevated risks of becoming infected with, developing, and experiencing continued high TB rates (Health Canada, 2012; Loppie Reading & Wien, 2009; Waldram et al., 2006).

Current literature on TB in Aboriginal populations acknowledges there are longstanding issues that continue to promote the spread and existence of TB however; it has done little to address the differences in TB experiences for Aboriginal peoples across community settings and the implications of TB policies. Recent studies have shown that TB continues to burden Aboriginal peoples and their communities due to long-lasting effects of previous treatment (i.e., sanatoria), the lack of awareness and education of TB (which promotes stigma), and many of the socio-economic inequities highlighted above (i.e. overcrowded housing, living in poverty) (Brassard, Anderson, Menzies, Schwartzman, & Macdonald, 2008; Gibson, Cave, Doering,

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[7] See First Nations Child & Family Caring Society (2013) for more information on Jordan's Principle and insight into how the fragmentation of health services affects Aboriginal peoples.

Ortiz, & Harms, 2005; Macdonald, Rigillo, & Brassard, 2010; Moffatt, Long, & Mayan, 2013; Moffatt, Mayan, & Long, 2013). In an effort to address the health disparity Aboriginal peoples face with regards to TB, the federal, provincial, and territorial governments have partnered together in an attempt to fight the spread of TB and provide all Canadian citizens with timely and accessible diagnosis and treatment.

Provincial TB policies co-exist alongside federal policies and strategies. Health Canada's (2012) *Strategy against Tuberculosis for First Nations On-Reserve* establishes clear guidelines and practices for TB diagnosis and treatment. Tuberculosis treatment will be further explored in the literature review, however, it is important to note that both federal and provincial policies require individuals with active TB to be isolated to ensure that treatment can be initiated and that TB is not spread further. *Where* the individual is required to be isolated is province dependent. Treatment can be either patient-centered (individuals are required to isolate themselves in their own home) or hospital-based (individuals are required to remain in a hospital isolation room). These provincial and territorial policies are clearly influential on the TB experience as individuals receiving treatment may be removed from their communities, over varying distances, away from their support networks, and disconnected from their cultural ties. As such, the TB experience cannot be understood without a full appreciation of where isolation occurs according to the provincial TB policies. To understand why Aboriginal peoples living in the Prairie Provinces are continuing to experience some of the highest TB rates in Canada, this study examined the TB experience of Aboriginal peoples living in different community settings in the Prairie Provinces.

The Current Study

The study relied on secondary data from a larger multi-province collaborative research project titled, *The Determinants of TB Transmission among the Canadian-born Population of the Prairie Provinces* (*DTT Project*). The *DTT Project,* which will be described in more detail in "Chapter 3: Methods", was a mixed methods study funded by the Canadian Institutes of Health Research (CIHR) and Health Canada. *The DTT Project* spanned seven years and included interviews with Aboriginal peoples who, at the time of being interviewed, were being treated for infectious pulmonary TB. By examining the TB experiences of Aboriginal peoples living in various community settings across the Prairie Provinces, this study has the potential to provide important information for (a) addressing current gaps in the TB literature; (b) enhancing understanding of how TB is experienced across different community settings; (c) improving current TB policy and practice.

Organization of Thesis

This thesis comprises nine chapters (including this introduction). Chapter two presents the literature that is relevant to the topic of study, including the health disparities between Aboriginal and non-Aboriginal populations, a description of TB, historical accounts of prevalence and treatment, current TB rates and studies in Canada, Aboriginal peoples access to health services in various community settings, and finally TB policies. Chapter three focuses on the research methodology and provides information on the method of focused ethnography and the use of secondary qualitative data. Chapters four through eight outline the findings of the study. Finally, chapter nine concludes the thesis by identifying the key finding that cut across all four findings chapters. Further to this, chapter nine outlines how this study addresses important gaps in current TB literature and the implications for TB policy and practice, as well as for future research related to addressing the disparities Aboriginal peoples living in various community settings face when they become infected with TB. Limitations of the study are also discussed.

Personal Positionality

It has been acknowledged by researchers (e.g., Griffiths, 1998) that it is important to recognize and provide context to the ideologies and perspectives that can lead to possible research bias. For this reason, I provide an overview of my background to position myself in this research. It was through my time as a frontline worker, a research assistant, and a student that I became a large advocate for Aboriginal social justice issues. When I entered my Master’s program, I was a frontline worker involved with Child Welfare in Alberta. Throughout my time in this role, I consistently observed that most of the families I worked with were of Aboriginal descent. In my desire to understand why this was the case, I began to immerse myself deeply in both academic and grey literature and sought opportunities to strengthen my relationship with Aboriginal communities. I had the privilege of being invited to Aboriginal community events in Edmonton as well as in surrounding reserve communities, which I attended with full appreciation and honour. I started talking more with the families I worked with to get first-hand accounts of how they became involved with Child Welfare and was repeatedly met with similar stories; they were the children of residential school survivors and experienced harsh intergenerational traumas brought on by this government instituted policy. In my search for understanding, it became clear to me that Child Welfare was not the only area Aboriginal peoples were disproportionately represented. Thus, when I was presented with the opportunity to conduct secondary analysis on the interviews from the *DTT Project,* I began an important journey of learning about the holistic impact diseases can have, not only on an individual or a community, but on an entire population.

As someone who does not identify as Aboriginal, I am acutely aware that my standpoints, worldviews, and understandings of health and community are shaped by my own upbringing, experiences, gender, and ethnicity. These factors shaped my narrow perception of what I understood health and community to be, in spite of my immersion in Aboriginal literature and culture. I went into this study with the acknowledgment that these narrow views on health were not going to necessarily align with the views of the Aboriginal peoples involved in the *DTT Project* and was prepared to gain a more holistic understanding.

The experiences the participants shared were deeply personal, sometimes heartrending, and I wanted to honour their stories to my greatest capabilities. This meant that my continued connection with Aboriginal peoples and their communities was very important throughout my Masters journey. I built a close relationship with an Elder prior to setting out to do this research and this relationship became critical not only for my own personal wellbeing but for continued support as I read and re-read the participants' interviews. I turned to this Elder for confirmation that this research was important and that it had the potential to bring positive changes to how Aboriginal peoples are experiencing TB today. Most importantly, by engaging in ceremony and having access to this Elder, I was provided with the emotional and spiritual support needed to confront the often difficult emotions that came along with doing this research.

CHAPTER 2: LITERATURE REVIEW

At the peak of the TB epidemic (late 1800s), mortality rates were 200 per 100,000 Canadians, and the disease was disproportionately affecting Aboriginal peoples and their communities (Long et al., 2013; Statistics Canada, 1992; Waldram et al., 2006). Yet, even within the Aboriginal population, there were disparities in TB rates. While the disease devastated some Aboriginal communities, others remained comparatively untouched (Daschuk et al., 2006). In the early 1900s, Aboriginal peoples who lived in the Prairie Provinces were found to be 20 times more likely to die from TB (Sproule-Jones, 1996). In 2015, TB continues to exist and disproportionately affect Aboriginal peoples living in the Prairie Provinces. The latest statistics show that in 2012, of the new cases presented in Alberta, Saskatchewan and Manitoba, Aboriginal peoples accounted for 9.2%, 70.1% and 62.3%, respectively (Public Health Agency of Canada, 2013). The primary research goal of the current study was to understand these disproportionate rates by examining the TB experience for Aboriginal peoples living in different community settings across the Prairie Provinces. This required the review of literature in six focal areas including the health disparities experienced by Aboriginal peoples, the bacteria that cause TB, the history of TB and TB treatment in Canada, current TB rates and studies in Canada, the access to health services in urban settings and remote and isolated reserve settings, and federal and provincial TB isolation policies.

A literature search was completed through the following database search engines: Academic Search Complete, Indigenous Peoples: North America, Native Health Databases, Health Systems Evidence, Health Policy Reference Center, and PubMed. The following key words were used to locate relevant research: tuberculosis, Aboriginal, First Nations, Native, Indigenous, health care, health services, disparities, on-reserve, and urban.

Health Disparities Experienced by Aboriginal Peoples

Aboriginal peoples experience many health disparities that extend beyond TB. Aboriginal peoples comprise roughly 5% of the Canadian population, yet, are far more likely to live in poverty, be unemployed, not graduate from high school, face addiction issues, commit suicide, and suffer from physical and sexual abuse when compared to the general population of Canada (Place, 2012; Trumper, 2004). Colonial policies (e.g., the Indian Act, residential schools, the reserve system), which sought to eradicate the language, culture, and familial ties of Aboriginal peoples, have had intergenerational impacts on their health and well-being (Aboriginal Affairs and Northern Development Canada, 1996; Greenwood & de Leeuw, 2012; Loppie Reading & Wien, 2009). The effect of these early government policies continues, and has been linked to many of the health and social disparities Aboriginal peoples face (Greenwood & de Leeuw, 2012; Loppie Reading & Wien, 2009).

High rates of substance abuse, domestic violence, and homelessness have been linked to disparities in health such as increased rates of diabetes, heart and liver diseases, and TB (Aboriginal Affairs and Northern Development Canada, 1996; Loppie Reading & Wien, 2009). Tjepkema (2002) found that Aboriginal peoples are more likely to engage in heavy drinking and substance use, which contribute to higher rates of mental health problems such as depression. Further to this, the Aboriginal population experiences poorer health at a younger age (Wilson & Cardwell, 2012). These complex social issues have led to generations of Aboriginal peoples experiencing higher rates of morbidity and mortality than non-Aboriginal Canadians (Frolich et al., 2005). The life expectancy of Aboriginal peoples in Canada is seven years shorter and their infant mortality rates are 40% higher than those of non-Aboriginal peoples (Indian and Northern Affairs Canada, 2004; Kirmayer et al., 2007).

A large number of Aboriginal peoples live in communities that have notably high levels of poverty, poor housing conditions, and limited health services (Aboriginal Affairs and Northern Development Canada, 1996; Beavon & Cooke, 2003). The underfunding of important resources and services (e.g., education, health services) significantly contributes to the poor health situation many Aboriginal peoples currently experience (Browne et al, 2009; Loppie Reading & Wien, 2009). The underinvestment by the federal government in reserves has been linked to lower levels of education and income, which act as barriers to living a healthy lifestyle, communicating effectively within a clinical context, and accessing health services (Benzeval, Taylor, & Judge, 2000; Schillinger, Barton, Karter, Wang, & Adler, 2006). These barriers in turn, contribute to diagnosis delays, thus promoting the spread of illnesses (National Collaborating Centre for Aboriginal Health, 2011), including TB.

Introduction to Mycrobacterium Tuberculosis

Alberta Health (2013) provides a comprehensive explanation of TB, which is summarized in this section. Mycrobacterium tuberculosis is the originating agent of TB in humans. Tuberculosis can affect any organ in the human body but presents predominantly in the lungs. The infection is transmitted through inhalation of the tubercule bacillus in droplet form (e.g., coughing, sneezing). Exposure needs to be prolonged for transmission to occur unless the individual carrying the bacteria is highly infectious, which significantly increases transmission time to only a few minutes. Optimal transmission conditions are humid and poorly circulated environments, and among individuals who are immunocompromised[8] (e.g., silicosis, HIV/AIDS, carcinoma). The rate at which the bacteria grow is typically very slow and has a doubling time of

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[8] Individuals who are immunocompromised are incapable of developing a normal immune response to fight off illness, usually as a result of disease and malnutrition (Mahon & Stiller, 1987).

15-20 hours. Symptoms vary because of the slow presentation and can differ greatly depending on the location of the disease. Typical TB symptoms include a bad cough that lasts longer than three weeks, weakness or fatigue, weight loss, a loss of appetite, chills, fever, and pain in the chest. A TB infection does not necessarily lead to active TB. Latent TB Infection (LTBI) is when the bacteria is present but the body has the immunity to fight the bacteria from growing. A person can live with LTBI and never experience symptoms or become sick with TB. Individuals with LTBI are not contagious, however, if the body cannot fight the disease (i.e., becomes immunocompromised), the LTBI can become active TB and require treatment.

There are two tests currently used to detect TB infection, a skin test (also known as a Mantoux test) or a blood test. These two tests are used only to determine if a person has become infected with the TB bacteria. To identify if the infection has progressed to active TB disease, a chest X-ray or a sputum sample must be obtained. In order to effectively treat TB, a combination of anti-TB drugs are given over a period of time, often between 6 and 9 months. Tuberculosis drug therapy is to be administered through directly observed therapy (DOT – a patient is given their medication by a health professional) to provide optimal results. In instances where individuals are highly contagious with active TB (sputum positive), they are isolated, typically in a hospital setting in a negative pressure room (where no air flows out into adjacent rooms). The objectives of TB treatment are to (a) kill the TB bacilli to prevent complications, further transmission, or death; (b) prevent the appearance or exacerbation of drug resistance; (c) prevent the relapse of disease after treatment is completed. During the initial phase (also known as front-end loading), anti-TB medications are administered around five times a week and are combined together to reduce the bacteria, relieve symptoms, and help prevent drug resistant TB. The continuation phase uses fewer medications, administered twice a week, and is targeted at eliminating any of the TB bacteria to ensure that no relapse occurs. *Where* treatment occurs varies across the Prairie Provinces, which is described later in this chapter.

History of Tuberculosis in Canada

Tuberculosis has a lengthy history in Canada and the policies and practices around the disease have continuously been developed or adapted as TB continues to impact individuals across the country. Around the time of confederacy in Canada, TB was considered the most pressing health problem facing Canadians and was a leading cause of death (Canadian Public Health Association, 2009; Wilkins, 1996). The origins of TB in Canada have often been debated (Daschuk, 2013). While it is argued by some that TB was present prior to the colonial settlement of European immigrants, others believe that European settlers brought TB to Canada (Daschuk, 2013; Grzybowski & Allen, 1999). Regardless of its origins, it is largely recognized that the social conditions (e.g., the reserve system) following European colonization inflated the TB rates to epidemic proportions (Hoeppner & Marciniuk, 2000). At the peak of its epidemic in the late 1800s, TB mortality was 200 per 100,000 Canadians (Statistics Canada, 1992).

The TB disease followed the construction of the Canadian Pacific Railway, from eastern Canada towards the west, which meant that Aboriginal peoples living in the Prairie Provinces were the last to be exposed (Grzybowski, 1983). Grzybowski argues that, because they were among the last to be exposed, the Aboriginal peoples on the Prairies did not have the opportunity to build immunity. Furthermore, reserves with deplorable living conditions were established and diseases were able to spread more rapidly. Daschuk et al. (2006) found that after the establishment of the reserve system and treaties[9], TB rates wreaked havoc on the health and well-

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[9] A treaty enabled the government of Canada to pursue agriculture, settlement, and resource development. Aboriginal peoples gave up areas of land in exchange for reserve lands and benefits such as the right to hunt and fish

being of Aboriginal peoples. In 1903, Dr. Peter Bryce, then Chief Medical Officer for the Department of the Interior and Indian Affairs, reported in the *Canadian Association for the Prevention of Tuberculosis Report* that the disproportionate amount of Aboriginal peoples infected with TB was directly related to the living conditions on-reserve. He noted that the spread of TB was enabled through unsanitary conditions of the reserves as well as the poor conditions of the residential schools. *The Story of a National Crime* was a formal criticism, later published by Dr. Bryce, on the deliberate and systematic approach the Department of Indian Affairs took to treating Aboriginal peoples (Bryce, 1922).

In the early 1900s, Aboriginal peoples who lived in the Prairie Provinces were found to be 20 times more likely to die from TB than their non-Aboriginal counterparts (Sproule-Jones, 1996). During this time, TB had become a national issue and the federal government sought effective interventions to stop the spread of the disease (Waldram et al., 2006). It is believed that TB has a possible 100-year lifespan within a community when interventions such as treatment regimes are not in place (Grzybowski & Allen, 1999). The government was aware of the general population's fear of the spread of the disease, which led them to establish the first sanatorium in Canada in 1897 (Archives of Ontario, 2011).

History of Tuberculosis Treatment in Canada

Sanatoria (long-term medical facilities) were established to treat patients, regardless of whether a patient was Aboriginal or non-Aboriginal, with rest-cure and open-air rehabilitation (Grzybowski & Allen, 1999; Health Canada, 2012; Waldram et al., 2006). It was argued that sanatoria promoted healing and prevented transmission by exposing patients to proper nutrition,

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(Aboriginal Affairs and Northern Development Canada, 2010, Treaties with Aboriginal People in Canada section, para. 5).

relaxation, fresh air, and sunlight (Long, 2007). The cost of attending sanatoria would sometimes be supported through charitable organizations (Wherrett, 1977) however, patients who were deemed financially capable were required to pay for their own treatment, causing many to return home penniless (Houston, 1991). In 1929, Saskatchewan was the first province to provide free sanatoria treatment to their residents at Fort Qu'Appelle, followed by Alberta in 1936, and Manitoba shortly thereafter (Baker, 1949; Wherrett, 1977). By 1938, every province across the country had sanatoria established (Grzybowski & Allen, 1999).

During this time, Aboriginal peoples were experiencing some of the highest TB rates. Aboriginal peoples were regarded as a generally unhealthy and disease-filled population (Kelm, 1998), and were therefore blamed by medical professionals for spreading the illness. As fear of the rapidly spreading TB grew, the Canadian government was pressured to further isolate sick Aboriginal peoples as a means of preventing non-Aboriginal peoples from contracting the disease (Lux, 2010). From 1945 to 1950, Aboriginal peoples were designated their own beds in hospitals across the country, under Canadian Indian Health Services, or were treated in hospitals that were specifically built to house Aboriginal peoples for any medical concerns (Drees, 2010; Shedden, 2011). Prior to effective TB drug therapy programs, medical interventions were invasive and patients experienced an extensive recovery period (sometimes over a year) (Grzybowski & Allen, 1999). Collapse therapy, where one of the patient's lungs was collapsed and ribs were removed to provide the lung with time to rest, was a common form of surgery (Grzybowski & Allen, 1999). In the 1960s anti-tuberculosis drugs were developed and the number of surgeries rapidly declined (Grzybowski & Allen, 1999).

Research documenting the experience of Aboriginal peoples being treated for TB has found that Aboriginal patients went through traumatic experiences that left long-lasting impacts on their communities and family members (Drees, 2010; Kelm, 2005; Moffat et al, 2013; Olofsson, Holton, & Partridge, 2008). It has been noted that public health officials would use coercive tactics (e.g., withhold funding to reserves until the band members submitted to an X-ray) to force Aboriginal peoples to be admitted to the nearest sanatoria (Lux, 2010; Shedden, 2011). Often, Aboriginal TB patients were removed from their communities in order to isolate the disease and prevent further transmission. Every individual suspected of being infected with TB was required to attend a sanatorium, however, the implications for Aboriginal peoples, who often only spoke their First language and were far removed from their communities, have been far reaching. These include painful and scarring memories of lost family members and the fear of being arrested when symptoms of illness were present (Shedden, 2011).

The treatment in the sanatoria was administered by non-Aboriginal staff, who lacked the capacity or language to explain the process to the Aboriginal patients. As a result, Aboriginal patients who lacked information about the disease and treatment were confused and frightened about the experience (Drees, 2010; Moffatt et al., 2013). Former sanatoria patients have described their inability to practice traditional healing methods as contributing to feelings of loss and disconnect from their culture (Moffatt et al., 2013). Because of poor patient records, Aboriginal patients often died in the sanatoria without their families being notified (Health Canada, 2012; Kelm, 2005; Olofsson et al., 2008). Those who survived treatment were often unable to return home, as they did not know where they were or how to get back to their families (Kelm, 2005). As a result of this history of TB treatment and the negative experiences for Aboriginal peoples (Moffatt et al., 2013), it is not surprising that feelings of mistrust amongst Aboriginal peoples towards health services and the fear of permanent displacement continue to impact their willingness to seek help and follow through with TB treatment (Health Canada, 2012; Macdonald, et al., 2010).

Experiencing Tuberculosis in Canada Today

Current national trends show that Canada is on par with many other developed nations in the fight against TB. However, in looking at the Prairie Provinces and specifically to the incidence rates experienced by Aboriginal peoples, TB continues to be an important health issue affecting Canada. While the national average of TB was 4.8 per 100,000 in 2012, the Prairie Provinces consistently experience higher rates with Alberta, Saskatchewan and Manitoba at 5.1, 8.4, and 10.8 per 100,000, respectively (Public Health Agency of Canada, 2013). The TB rates for all three provinces have shown little improvements in the last decade and in some years have actually increased in spite of advancements in policy administration and treatment. If these trends continue, there will be an even greater need to understand the conditions in which this disease is able to persist. The data for the larger *DTT Project* were collected between 2006 and 2013. The rates of new, active, and re-treatment tuberculosis cases collected by the Public Health Agency of Canada between 2006 and 2013 are displayed in Table 1.

Table 1

Reported New, Active, and Re-treatment Tuberculosis Cases and Incidence Rates per 100,000 in the Prairie Provinces and Canada

Reporting Year		Canada	Alberta	Saskatchewan	Manitoba
2006	Cases	1,653	131	87	134
	Rate	5.1	3.8	8.8	11.3
2007	Cases	1,575	112	105	103
	Rate	4.8	3.2	10.5	8.6
2008	Cases	1,644	167	97	141

Reporting Year		Canada	Alberta	Saskatchewan	Manitoba
	Rate	4.9	4.6	9.6	11.7
2009	Cases	1,655	176	90	156
	Rate	4.9	4.8	8.7	12.8
2010	Cases	1,587	134	81	132
	Rate	4.7	3.6	7.8	10.7
2011	Cases	1,618	170	83	116
	Rate	4.7	4.5	7.8	9.3
2012	Cases	1,685	196	91	137
	Rate	4.8	5.1	8.4	10.8
2013*	Cases	1,640	187	85	169
	Rate	4.7	4.6	7.7	13.4

**2013 is based on pre-release data and are provisional until the latest Tuberculosis in Canada surveillance report is released.*

Note. Adapted from Public Health Agency of Canada (2015), Tuberculosis in Canada Pre-Release 2013

Within these numbers, a look at the populations specifically being affected show a large burden of the disease being experienced by Aboriginal peoples and reflect one of the major health disparities they face today. In 2012, of the new cases presented in Alberta, Saskatchewan, and Manitoba, Aboriginal peoples accounted for 9.2%, 70.1%, and 62.3% respectively (Public Health Agency of Canada, 2013).

Tuberculosis in Aboriginal Peoples

The majority of TB studies are conducted in developing countries where their citizens are continuing to be affected by TB, despite advances in policy and treatment around the world. In

Canada, a handful of researchers are trying to understand why TB is able to persist in a country that does not face as many health barriers and economic hardships as do developing nations (e.g., Brassard et al., 2008; Macdonald et al., 2010; Moffat et al., 2013). As highlighted in Table 1, the current Canadian trends in TB show that there has been an overall decline in the disease; however, Aboriginal peoples and the Prairie Provinces continue to face disproportionately high rates. Various studies have examined TB and its continued presence in Aboriginal reserves (Gibson et al., 2005) and among urban Aboriginal populations (Macdonald et al., 2010). One of the largest and overarching findings across the current research is that the limited knowledge and awareness about TB continues to impact the high rates experienced by Aboriginal peoples (e.g. Alvarez et al., 2014; Gibson et al., 2005; Macdonald et al., 2010). Limited knowledge and awareness leads to a fear of being diagnosed and a continuation of the negative legacies of sanatoriums.

Alvarez et al. (2014) conducted a mixed methods study in Iqaluit, Nunavut to develop, implement, and evaluate the effectiveness of a public health campaign to complement existing efforts that relied on contact tracing/investigations[10] for identifying TB cases. The results from this study showed that the awareness campaign increased the number of people requesting testing. However, the increase did not continue after cessation of the campaign. Brassard et al. (2008) conducted a qualitative exploration of the knowledge and perception of TB among Aboriginal participants in Montreal. Their findings revealed that there is a continued lack of knowledge and misconceptions about TB, which act as barriers to controlling the disease. In another qualitative study in Montreal, Macdonald et al. (2010) sought to understand the

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[10] TB patients are required to identify individuals they have had previous prolonged contact with. These individuals are contacted and informed of the potential TB infection and are requested to complete a TB test.

experience of TB in urban Aboriginal participants. Their interviews revealed that participants, while having experiential knowledge of TB, lacked biomedical awareness and knew very little about how they acquired and could pass on the disease. Many of the participants had negative previous experiences with health services, feared positive test results, and worried about the burden of long-term treatment. They also recounted negative memories related to colonial TB treatment.

The mistrust Aboriginal peoples feel towards health services has been found in other studies (Gibson et al., 2005) and is linked to the traumatic legacy sanatoriums have within the Aboriginal population (Macdonald et al., 2010; Moffatt et al., 2013). Gibson et al. conducted a mixed methods study using a participatory action research approach[11] to understand the socio-cultural factors that influence behaviours related to TB within immigrant and Aboriginal populations in Alberta. The findings showed that the stigma associated with having TB was more prevalent among the Aboriginal participants as they believed their diagnosis reflected poorly on them. Further to this, the participants in this study reflected on their own negative perceptions and experiences with sanatoriums which they believed influenced their desire to seek medical attention.

In a qualitative study conducted by Moffatt et al. (2013) with TB patients being treated in isolation in a hospital, it was found that sanatorium and Canadian colonial legacies continue to impact Aboriginal peoples living on-reserve in Alberta. Participants described losing their culture, being fearful of the health professionals, and experiencing sadness over not being able to

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[11] Participatory action research is defined by its approach to improving health research based through involving the people who are directly affected by the research and will in turn improve their own health (Baum, MacDougall, & Smith, 2006)

use traditional healing methods to get better. In spite of sanatoriums no longer being used, participants expressed fear over becoming sick and having to return to sanatorium like conditions as they viewed all health services as largely negative. When the participants in this study returned to their reserve communities after treatment, they felt stigmatized against and like outsiders.

The studies above are similar in their findings for both on-reserve and urban Aboriginal participants, with respect to knowledge and education and the legacy of sanatoriums. However, there were some unique features that specifically depended on the community setting of the participants. Within the study conducted by Macdonald et al. (2010), which looked to understand the experience of TB for urban Aboriginal participants, it was found that their participants attributed living on the street, smoking too much, and engaging in drug use to their inability to identify their early presenting TB symptoms. It was noted that they lacked awareness over where a diagnosis could be sought and where appropriate testing could be conducted; this allowed the disease to get worse and spread further. These participants did acknowledge positive relationships they had formed with service providers at the local Native Friendship Centre, which facilitated their access to health services. Moffatt et al. (2013) identified that over-crowded (multiple family members sleeping in the same room) and inadequate housing (poorly constructed, poorly ventilated, uninhabitable) on-reserves continued to impact high TB incidence rates. The effect of over-crowded housing was linked to addictions issues and a lack of control, which created an environment that promotes the spread of infectious diseases. Studies such as those conducted by Macdonald et al. and Moffatt et al. are important as they highlight critical aspects of the TB experience that are different for Aboriginal peoples living on-reserve and those living in urban centres.

Clark and Cameron (2009) conducted a study to predict the future disease burden of TB, and it was determined that eliminating TB among Aboriginal peoples in Canada was possible only through investment in programs that were designed to control and prevent transmission. Current programs and services to diagnosis and treat TB are community and province dependent, and largely provided by provincial, territorial, and federal health services. Access to health services has been identified as a large barrier to health promotion for Aboriginal peoples (Loppie Reading & Wien, 2009) and is an important factor in understanding their TB experience and current high TB rates.

Access to Health Services across Community Settings

Aboriginal peoples live in a variety of different community settings including urban, non-remote reserve, remote reserve, and isolated reserve. An urban centre is separated by Statistics Canada (2011) into (a) a small population centre with a population between 1,000 and 29,999; (b) a medium population centre with a population of between 30,000 and 99,999; (c) a large urban population centre consisting of a population of over 100,000. For simplicity, “urban centre” will be used as an overarching term throughout this thesis for the three types of population centres. Health Canada (2012) defines a non-remote reserve as being located under 350 km from an urban centre. A remote reserve community is a “geographical area where a First Nations community is located over 350 km from the nearest service centre having year-round road access” (p.28). Finally, an isolated reserve community is a “geographical area that has scheduled flights and good telephone services, however it is without year-round road access” (p.27). Aboriginal peoples who live in these different community settings experience various barriers in regards to health promotion and often struggle with poor determinants of health (Health Canada, 2012; Loppie Reading & Wien, 2009; Marchildon, 2005). Access to health services has been identified as a significant determinant in health promotion among Aboriginal peoples (Loppie Reading & Wien, 2009) and is an important factor in understanding the TB experience.

Today, nearly all Aboriginal reserves, with the exception of a few that are located near urban centres, have access to health services located on-reserve through a community health centre or a nursing station (Healy & McKee, 2004). It has been noted that despite this, Aboriginal peoples living on non-remote reserves have easier access to and frequent the health services offered in urban centres due to proximity (Healy & McKee, 2004). Administration and delivery of health services offered in urban centres fall under provincial jurisdictions, which include physician and hospital care (Health Canada, 2012). Urban centres across the Prairie Provinces offer primary, secondary[12], and tertiary[13] levels of care.

Primary care is the first point of contact an individual has with the health system; this includes prevention, diagnosis, referral, treatment, and follow-up for health conditions (Health Canada, 2012). Family physicians, nurses, and emergency room doctors are typically the first point of access to primary care (Health Canada, 2012). Research has found that urban Aboriginal peoples, as well as those from non-remote reserves, have higher rates of emergency room access and frequent a family physician less often than non-Aboriginal peoples (Firestone, Smylie, Maracle, Siedule, & O'Campo, 2014). When Aboriginal peoples do access health services in urban centres, they face discrimination, feel excluded and ignored, and are typically unable to receive culturally sensitive services (Adelson, 2005; Browne, 2005; Place, 2012; Sookraj,

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[12] Secondary health services are provided by physician specialists and require the primary physician or nurse to provide a referral (Health Canada, 2012).

[13] Tertiary care is often highly specialized and only accessible in large urban centres where there are advanced technologies and medical facilities (Alberta Physician Link, 2012).

Hutchinson, Evans, & Murphy, 2012; Tang & Browne, 2008). All of these barriers result in Aboriginal peoples having negative experiences with health services and ultimately unmet health needs (Tjepkema, 2002).

Aboriginal peoples living in remote and isolated reserves also experience barriers in accessing appropriate health services. Remote and isolated reserves have varying levels of available health services, which can further magnify health conditions. In isolated and remote reserves south of the 60th parallel, nursing stations are in place for community members (Health Canada, 2015). The large cost of service delivery to remote and isolated reserves has reduced availability of health services (Halseth & Ryser, 2006). As very few northern remote and isolated reserves have year round access via roads, these nursing stations are staffed almost entirely by nurses for a majority of the 24 hours a day the stations are open (Tait, 2008). Nursing stations provide basic levels of primary care where the focus is on assessment, treatment, and emergency services (Health Canada, 2015). In these communities, nurses often serve as the main point of contact for individuals accessing health services (Health Canada, 2015). Nurses typically facilitate new baby care, provide immunizations, present education seminars, provide primary care services during scheduled clinic visits, and attend to emergency needs (e.g., trauma, cardiac conditions) (Health Canada, 2015).

While nursing stations are available for community members, the level of care and resources have often been described as inadequate and insufficient (Halseth & Ryser, 2006; Loppie Reading & Wien, 2009). Research has shown that the health services offered in remote and isolated reserves in Canada often lack qualified health boards to support the administration and delivery of care to community members, resulting in unmet health needs (Halseth & Ryser, 2006; Loppie Reading & Wien, 2009; Public Health Agency of Canada, 2013). Furthermore, nursing stations face staffing shortages, high turnover rates, a lack of diagnostic services, and a lack of qualified Aboriginal health professionals that can offer culturally competent care (Public Health Agency of Canada, 2013). These conditions often require many Aboriginal peoples to travel to urban centres outside their community (depending on climate and available transportation) to access health services (Halseth & Ryser, 2006; Public Health Agency of Canada, 2013).

As highlighted above, Aboriginal peoples living in different community settings (urban centres as well as non-remote, remote, and isolated reserves) face their own unique challenges in regards to access to health services. Negative experiences and a lack of appropriate resources and services has a harmful impact on Aboriginal people's desire to seek medical care which exacerbates their high TB rates (Browne & Fiske, 2001). As such, access to health services is an important aspect in understanding the TB experience for Aboriginal peoples living in different community settings. As many communities do not have the necessary services in place to treat TB, individuals must be removed from their home and/or community to begin treatment. The impact that isolation policies have on individuals seeking treatment, depending on the province in which they reside, can have long lasting outcomes as the individuals must remain in isolation for a number of weeks.

Federal and Provincial Tuberculosis Policies

To prevent and control TB, the federal, provincial, and territorial governments have taken on a shared responsibility to provide individuals with timely and accessible diagnosis and treatment that would prevent further transmission. The nature of Aboriginal funding for health was, and is still, a complicated matter. Federally funded health related services are offered to Aboriginal peoples who reside on-reserve. However, access to these programs depends on complex rules behind status[14], treaty, band membership[15], residency, and provincial and federal legislation (Browne et al., 2009). While the federal government has authority over Aboriginal reserves, each province and territory is in control of their own health services, which requires Aboriginal peoples who no longer live on-reserve to access health services provided by the provincial government (Fitzgerald, Wang, & Elwood, 2000; Healy & McKee, 2004; Long, 2002). Research on the implications of these funding jurisdictions suggests that the complications that arise from jurisdictional miscommunications and the need to cross jurisdictional lines to access health services negatively impact Aboriginal people's health (National Collaborating Centre for Aboriginal Health, 2011; Waldram et al., 2006). The policies surrounding TB instituted in each province appear to clearly identify the authority over and the process for the diagnosis and treatment of TB between the federal and provincial/territorial governments.

Federal TB Policy

The following information was retrieved from Health Canada and the Public Health Agency of Canada's (2014) *Tuberculosis Prevention and Control in Canada - A Federal Framework*. The Public Health Agency of Canada provides national level leadership on all TB matters while working collaboratively with both provincial and international partners. The Public

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[14] "An individual recognized by the federal government as being registered under the Indian Act is referred to as a Registered Indian (commonly referred to as a Status Indian). Status Indians are entitled to a wide range of programs and services offered by federal agencies and provincial governments. Over the years, there have been many rules for deciding who is eligible for registration as an Indian under the Indian Act. Legislation varies across the ten provinces and three territories and so do the services available to Canadians in general and to Aboriginal people in particular. What you are eligible for depends largely on where you live" (Aboriginal Affairs and Northern Development Canada, 2013, Indian Status section, para.1).

[15] "Prior to 1985, automatic entitlement to band membership usually accompanied entitlement to Indian status. The 1985 amendments recognized the rights of bands to determine their own membership. As a result, persons may possess Indian status, but not be members of a band. Section 10 enables First Nations to enact their own membership or citizenship codes, according to procedures set out in the Indian Act" (Parliament of Canada, 2003, Registration and Band Membership Under the Indian Act section, para. 1).

Health Agency of Canada is in charge of monitoring the epidemiological trends of active TB and LTBI, providing support for outbreak management, enforcing measures of the Quarantine Act, and providing guidance on best practice in prevention, diagnosis and treatment. The cost of treating TB in Canada in 2004 was $74 million, with the average cost of treating a single active case being $47,000. The focus of the federal TB policy is to decrease national incidence rates in Canada to 3.6 per 100,000 by 2015, with the two target populations being Aboriginal and foreign-born individuals. The federal policy acknowledges that the high incidence rate of TB for some Aboriginal communities is caused by “overcrowding and poorly ventilated homes...poor nutrition....co-morbidities...[which] can be exacerbated in remote and isolated communities because of limited and/or delayed access to health care services” (p.4).

Federal On-Reserve TB Strategy

Health Canada’s (2012) *Strategy Against Tuberculosis for First Nations On-Reserve* is specifically designed to inform TB policies, both provincially and federally for Aboriginal peoples living on-reserve. The strategy document outlines that TB continues to be an ongoing concern plaguing many Aboriginal reserves and identifies the social factors, including overcrowded housing and poverty, that contribute to TB disparities between Aboriginal and non-Aboriginal peoples. The strategy document also outlines that these social conditions increase the progression of LTBI to active TB and can increase transmission rates among community members. Since Aboriginal peoples are a highly mobile population, emphasis is placed on strong collaboration between health systems. Without collaboration, there can be delays in diagnosis as well as a lack of continuity of care for patients who must begin treatment in a hospital and then return home to complete the entire prescribed regiment. Any interruptions in treatment can lead to resistant strains of TB and an increase in TB-related morbidity and mortality rates. The strategy is divided into three themes: Preventing, Diagnosing and Managing TB, Targeting Populations at Greatest Risk for TB, and Developing and Maintaining Partnerships.

All three themes are integral to achieving a comprehensive and responsive TB strategy that supports continued efforts of all parties (e.g., policymakers, doctors, patients). Under the first theme, one of the most important aspects in preventing TB is the need to promote a method of sharing information and education materials that is transparent and accountable. The strategy is meant to provide guidelines for collaboration with provincial governments as each province has jurisdictional structures and population needs that inform their own TB prevention and control strategies. Finally, there is an explicit need to foster community involvement and shared ownership of TB prevention and control activities, which is reflected in the third theme of developing and maintaining partnerships. Strong partnerships between provincial and federal service providers are integral in efforts to eradicate TB as it is necessary to provide a continuum of care while patients move on- and off-reserve and between provinces. While the federal government identifies best policies, it is up to the provincial governments to implement best practice. The practice around how TB treatment is administered varies between the Prairie Provinces.

Alberta TB Treatment Policy

The Government of Alberta's (2010) Tuberculosis Prevention and Control Guidelines follow the federal TB policy and adhere to the same goals around TB treatment and case management. Under the *Public Health Act*, Alberta has clear legislation around isolation of suspected TB cases, which states that all individuals who have active TB must remain in isolation until they are proven to be noninfectious (minimum two weeks). Alberta Health Services has the responsibility to ensure that individuals are isolated when they are suspected and/or confirmed to have infectious TB in order to control its spread. If individuals refuse or neglect to comply with conditions of TB treatment, they may be apprehended and detained. Further to this, for communicable diseases, Alberta Health Services provides drugs and treatment free of charge. The *Public Health Act* also gives the regional health authority the ability to conduct contact investigations and attempt to identify the source of the initial disease. Contact investigations are a critical component of TB control in all of the provinces.

Saskatchewan TB Treatment Policy

The Government of Saskatchewan has consistently established and developed their existing TB strategies and policies to fight the disease. In 2013, a five year strategy, *Saskatchewan Provincial Tuberculosis Strategy 2013-2018*, was instituted to address prevention, treatment, education, and control of TB (Government of Saskatchewan, 2013). In Saskatchewan, a patient-centered approach to treatment is taken whereby isolation is typically carried out in the patient's home with support from a community-based team. Home-based isolation requires patients to not leave their residence unless it is for urgent medical appointments and/or they must wear a mask if they do go out. The family of patients may be required to leave the home if they are at a high-risk of becoming infected (e.g., young children, individuals who are immunocompromised). Visitors are allowed in the home if the patient wears a face mask. Patients are encouraged to keep windows open and to go outside. If the patients are very sick from their TB they may require specialized TB treatment in a hospital setting. As such, they are brought into the hospital for a limited number of days and are then returned to their home to complete treatment. Saskatchewan is unique in that they provide mobile clinics outside of major urban centres to facilitate patient access to care in northern communities. Furthermore, Saskatchewan has started to use TeleHealth (using videoconferencing equipment) services to support patients, thus, decreasing their need to go to major urban centres for follow-up appointments.

Manitoba TB Treatment Policy

The Manitoba Tuberculosis Policy has a clear isolation policy for those infected with TB, which is similar to the Alberta policy (Government of Manitoba, 2014). Clients are typically required to stay in a negative pressure isolation room and are kept in isolation for a period of two weeks or more depending on how ill they are. The Minister of Health has the authority (also under the *Public Health Act*) to direct a peace officer to apprehend non-complying individuals and examine, treat, and detain them until they are no longer a threat to the public. Patients must produce three consecutive negative sputum smears to be able to leave isolation. The policy states that when patients require isolation, they are to be educated about permitted activities, limiting and excluding visitors, disposal of infectious material, and when discontinuation of isolation can occur.

Summary

The research on the TB experiences of Canadian Aboriginal peoples is very limited. Tuberculosis is no longer as common as it was a century ago, which can partly explain the lack of current research on this issue (Pan-Canadian Public Health Network, 2012). However, as Aboriginal peoples carry a large burden of the TB rates in Canada, it continues to be an important area of concern. They live in various community settings and face multiple barriers in terms of their health promotion. As such, in order to have a fuller understanding of the continued presence of TB affecting Aboriginal peoples, it is important to explore the TB experience for Aboriginal peoples living in different community settings across the Prairie Provinces. The following chapter will describe how the current study set out to answer this important research question.

CHAPTER 3: METHODS

Research Design

This research study drew on qualitative data from a larger research project. *The Determinants of Tuberculosis Transmission among the Canadian-born Population of the Prairie Provinces (DTT Project)* (Boffa, King, McMullin, & Long, 2011) was a seven year (April 1, 2006 to March 31, 2013), interdisciplinary, and participatory mixed-method study aimed at understanding the transmission rates of TB in Aboriginal and non-Aboriginal peoples from Alberta, Manitoba, and Saskatchewan. The *DTT Project* explored the environmental, biomedical, socio-cultural, and historical determinants of TB transmission. The research team was made up of social scientists, Aboriginal health researchers, clinicians, and epidemiologists. An Aboriginal consultative team based at the University of Alberta developed the project. Consultative committees, named Provincial Network Committees (PNCs), were established in each province and were composed of health professionals, Elders, traditional healers, Aboriginal and government stakeholders, and former TB patients. The PNCs were mandated to consist of over 50% Aboriginal peoples.

The current study drew on a focused ethnographic approach to examine the interview data collected through the *DTT Project* and to understand the TB experience for Aboriginal peoples living in different community settings across the Prairie Provinces. This chapter first outlines the rationale for drawing on a focused ethnographic approach to answer the current research question, followed by a description of recruitment, sample, and data sources used in the *DTT Project* to understand Aboriginal peoples TB experience. Finally, ethical considerations that went into this culturally sensitive study are illustrated and the steps taken to ensure rigour are delineated.

Secondary Analysis

This study used data collected from a larger research project. Secondary data analysis refers to the process of “using the data from a previous project to address new research questions” (Hammersley, 2010, para. 4). As such, secondary data analysis allows for the “prompt examination of current policy issues” (Vartanian, 2010, p.14), which this study seeks to do. Qualitative secondary analysis has often been associated with ethical controversies (Broom, Cheshire, & Emmison, 2009). As qualitative data are typically generated through interviews during which researchers form relationships with their participants, some researchers have raised concerns about the use of the data by other researchers and the ethics around informed consent (Irwin, 2013). Further to this, opponents to secondary analysis believe that the data cannot be properly interpreted due to a lack of knowledge and understanding of the context in which the data were originally collected (Gillies & Edwards, 2005; Parry & Mauthner, 2005). As noted by Vartanian (2010), there is a “lack of control over the framing and wording...[which] may mean that questions important to your study are not included in the data” (p.15). Moreover, the re-use of data does not allow the researcher to experience the nuances of emotions that often occur during interviews and are not written down thus, cannot inform a secondary analysis (Hammersley, 2010). This can further limit how data are interpreted.

Moore (2007), on the other-hand, has disputed these notions by arguing that many of the challenges faced in secondary analysis are similar to those of primary research. For example, primary research often relies on external documents that have been collected by previous historians and on data collected by a few, but not all, team members (Hammersley, 2010). Moore further argues that data are always constructed. This is largely due to the fact that the data are “constituted, contextualised, and recontextualised within any project” (Hammersley, 2010, p.2).

Interpretations are always being made by researchers whether it be during primary or secondary analysis and these interpretations do not always accurately reflect reality as they are a direct result of who the researchers are and their relation to the data being used (Hammersley, 2010; Heaton, 2008).

When conducting secondary analysis, it is important to understand the context in which data were collected as well as the purpose of the original study (Heaton, 2008). Heaton (1998) suggests that to be done well, secondary analysis should be reflective of the original research goals. The purpose of the *DTT Project* was to understand the determinants of TB transmission for Aboriginal peoples living in the Prairie Provinces; the current study is embedded in the original research purpose by seeking to understand the TB experience. The use of semi-structured interviews in the original research project allowed for a range of topics to be covered during the interview and variability in participants' responses. Semi-structured interviews produce data that are independent of the researcher (Irwin, 2013). As such, participants were asked a few questions and this led to participants organically telling their own stories and describing their entire or different aspects of their TB experience with occasional prompting from the interviewer. Participants reflected on becoming infected with TB and covered the wide range of influence TB had on their lives, thus making the data particularly suitable for secondary analysis. Heaton (1998) argues that when the secondary analysts are not part of the original research team, it is important that they have access to the primary researcher who can provide context to the material as well as provide the opportunity to check findings and interpretations. This study was conducted with access to many members of the original research team who provided important information on the initial context for the study as well as consistent support and guidance throughout the analysis and interpretations of the findings.

Focused Ethnography

Young (2003) notes that Aboriginal health needs are often under-researched but such research is crucial to effectively contextualize current health outcomes for Aboriginal peoples. In order to understand the factors that impact being infected with TB it is necessary to include the perspectives and voices of Aboriginal peoples in research (Meadows, Lagendyk, Thurston, & Eisner, 2003). Given the importance of understanding the experiences of Aboriginal peoples within their cultural contexts and the need to include Aboriginal perspectives in research, it was important to draw on a method that put these at the forefront of inquiry; that is, focused ethnography. Focused ethnographic studies are sensitive to and focus on cultures and sub-cultures that are studied in relation to a specific, identified, and discrete community problem (Higginbottom, Pillay, & Boadu, 2013). While an ethnographic study seeks to understand the cultural significance individuals in a specific group attach to their experiences through a broader lens, focused ethnographies take a different angle and look at addressing a distinct issue affecting a specific group (Cruz & Higginbottom, 2013). Focused ethnography is appropriate for health research as it has the potential to not only enhance understanding on topics of importance to a specific group, but also has the potential to determine ways to improve health services concerning a particular issue (Higginbottom et al., 2013). The findings from this study have implications for communities, policies, and practice (Higginbottom et al., 2013; Knoblauch, 2005; Roper & Shapira, 2000), as they are specific to an issue of pressing importance and are informed by Aboriginal people's perspectives.

Participant Recruitment

Participants of the *DTT Project* were accessed through medical professionals (e.g., doctors, nurses) across Alberta, Saskatchewan, and Manitoba. For participants to be eligible to participate in the *DTT Project*, they needed to be over the age of 14, Canadian-born, and diagnosed with culture-positive pulmonary TB in one of the Prairie Provinces between 2007-2008. Given the sensitive nature of researching a personal health experience, the clinic staff that had existing relationships with the patients, were asked to initiate the invitation to participate. The participants were first asked to complete a questionnaire which asked demographic questions (e.g., age, gender, occupation, education attainment) as well as questions about their TB (e.g., prior infections, symptoms, where they accessed their diagnosis). The patients who consented to the quantitative questionnaire (n=183) and who were highly infectious (sputum smear-positive) were further invited to participate in an interview (n=145).

When patients expressed interest, a *DTT Project* interviewer made arrangements to review the study information sheet on a day and time that suited the patient. Each province had a different interviewer, which included a TB nurse, an Aboriginal educator, and a health researcher. Participants signed a consent form in English. An interpreter was available in every province upon request. Participants over the age of 14, who were competent English-speakers and lived on their own, were able to provide their own informed consent with the interviewer as a co-signatory. If participants were between the ages of 15 and 17 and lived with their parent or guardian, the parent/guardian signed on the participants' behalf. Ultimately, 56 patients from various communities across the Prairie Provinces and from many different cultural groups (e.g., Cree, Dene, Ojibway) agreed to participate in the interviews.

Sample for this Study

Forty-eight of the existing 56 interviews were used for this secondary data analysis. The eight interviews that were not included were from a unique community setting, identified as a "Northern Village" in Saskatchewan. These participants lived in what would be deemed an "urban centre" in this study where the population was approximately 95% Aboriginal peoples. This Northern Village also consistently experiences a significantly high TB rate in comparison with other communities. The stories shared by the participants were unique and distinctive and could be studied in future research. Table 2 displays the provincial breakdown of the number of participants from each province within their community setting and their demographic information. The youngest participant in this study was 17 years old and the oldest was 62 years old. Participants were assigned their community setting based on where they lived at the time of their diagnosis taken from information collected in their quantitative survey.

Table 2

Participant Characteristics

Province	Community Setting	Gender	Age
Alberta	Urban Centre (*n*=7) Non-Remote Reserve (*n*=7) Isolated Reserve (*n*=0) Remote Reserve (*n*=0)	Male (*n*=8) Female (*n*=6)	*M* = 40.5
Saskatchewan	Urban Centre (*n*=6) Non-Remote Reserve (*n*=4) Isolated Reserve (*n*=4) Remote Reserve (*n*=2)	Male (*n*=6) Female (*n*=10)	*M* = 36
Manitoba	Urban Centre (*n*=8) Non-Remote Reserve (*n*=4) Isolated Reserve (*n*=6) Remote Reserve (*n*=0)	Male (*n*=8) Female (*n*=10)	*M* = 41.1

Saturation

Within focused ethnographies, data saturation often dictates the sample size (Higginbottom et al., 2013). There are a number of factors Morse (2000) identifies that should be considered when attempting to reach saturation in qualitative studies. The factors that were considered related to this study included (a) the quality of data; (b) the scope of the study; (c) the nature of the topic; (d) the amount of useful information; and (e) the qualitative method and study design used. The participants easily described the nature of the topic, as they were being treated for TB and continued to be impacted by the TB experience. This further impacted saturation as participants were able to provide a large amount of useful information directly related to the research question. They described their experiences well and were given time to walk through their entire journey. The quality of the interviews was very good and provided an in-depth look into the research question. The participants provided enough information that the research question could be answered and there were important contributions to be made to current TB research, policy, and practice.

Sources of Data

The interviews with the *DTT Project* participants were the primary source of data for the current study. To enhance the information gained from the interviews and to contextualize the findings about the participants' TB experience, two supplementary sources of information were used (a) a quantitative survey that identified the community in which the participants lived; and (b) community access forms (CAFs) to determine the kind of medical services available in the participants' home community. Given that the interviews are the focus of this study, they are described in more detail.

Interviews

A semi-structured interview format was used in the *DTT Project*. Core questions focused on (a) where participants felt their home was; (b) their sources of strength; (c) ties to the community; (d) perceptions of a healthy person; (e) what a typical day looked like prior to being infected with TB; (f) how they found out they had TB; (g) their experience in seeking a TB diagnosis; (h) what their prior TB knowledge was; (i) how their community felt about TB. The interview protocol went through an iterative review process with the PNCs. The three interviewers followed the semi-structured format, however, differences were observed across interviews, especially around what information was probed further and what questions were left out. Certain questions were not asked in some provinces, at the discretion of the interviewers, which may have been due to the flow of the conversation and/or limited timing.

The interviews were conducted in various locations depending on the province. In Manitoba and Alberta, the participants were being treated for their TB in a hospital setting and were typically in an isolation room. In these instances, the interviewer was required to wear a facemask, which participants expressed caused some discomfort as they had difficulty hearing and replying to questions. Participants also expressed sadness about being made to feel they were contagious and "dirty." Because the interviewers' voices were muffled by their facemasks, transcription was more difficult than usual. In Saskatchewan, interviews were conducted in a number of different locations including participants' homes, correctional facilities, hotels, and research and health services facilities, depending on where the participants were being treated or where they felt most comfortable. In most of the interviews the participants were very sick, and as such, interviews were sometimes cut short when participants indicated that they began to feel fatigued by the process. In these cases, follow-up interviews were difficult to schedule because participants were no longer receiving treatment under isolation in a hospital setting.

When the interviews were conducted in the hospital, they were occasionally interrupted by health and cleaning staff who would come in and out of the room, as well as by the patient's visitors. There were a few instances where a spouse or parent was present during the interview and contributed to the dialogue. The spouse or parent did not take over the process or interrupt the flow of the interview; rather, they were able to provide further insight into their perspective on the participant's experiences. Overall the quality of the interviews was very high and provided rich detail and depth into the participants' TB experiences.

The interviews were recorded, when permission was given (n=54), and transcribed by a professional transcriptionist. Detailed notes were taken for two of the interviews that were not recorded. Forty-eight of the interviews were used for the purpose of this study, which included the two non audio-recorded interviews. The interviewer added notes on some of the transcripts after they were completed commenting on how the interview went and anything of concern. It is important to note that the interviews were conducted shortly after participants had begun treatment. As such, the answers they provided in regards to becoming sick were retrospective. Questions in regards to how they felt about returning home and continuing treatment were answered prospectively, with the exception of Saskatchewan participants who had often returned home already for treatment. Regardless of where the participants were when they were interviewed, the insights they provided were important to consider in regards to understanding the entire TB experience.

Supplementary Documents

Quantitative Survey

In the *DTT Project*, the quantitative surveys were used to capture the demographic characteristics of the participants, where they sought TB treatment, if they had a family doctor, as well as if they had previously been infected by TB. From the quantitative data, the information about where the participants lived at the time of diagnosis was used to place participants into their community setting group to better understand the differences and similarities in TB experiences.

Community Access Forms

The First Nations Inuit and Health Branch (FNIHB) has documented the health services available on-reserve across Canada. Interviewers completed CAFs for participants who lived on-reserve at the time of diagnosis to capture the health services available that would support a TB diagnosis. The CAFs include information about (a) reserve type (e.g., isolated, remote, non-remote); (b) whether there is a health centre or nursing station; (c) how often a doctor is in attendance; (d) if there is a working X-ray machine and technician; (e) distance to the nearest X-ray machine; (f) if the community has a registered nurse, community health nurse, or a community health representative. Information from the CAFs is used in chapter eight, which discusses the impact of access to health services in the community on the TB experience.

Data Analysis

Interviews were analyzed using qualitative content analysis to answer the research question. This approach was chosen as it has the potential to "identify core consistencies and meanings" (Patton, 2002, p.453) in the data and lead to the generation of themes and codes (Hsieh & Shannon, 2005). The interview transcripts were already separated by the province where the interview occurred. Provincial groupings provided a practical point of organization and data management. Further to this, the differences in provincial TB policies were relevant to discussing the impact that isolation policies had on the TB experience. To begin, all of the interviews were grouped according to the type of community where the participant resided during the time of diagnosis: urban centre, non-remote reserve, remote reserve, and isolated reserve.

Interview transcripts were first read in their entirety to develop an understanding of the content before engaging in coding and in-depth analysis. The transcripts were then re-read and reviewed line-by-line with codes generated along the way to highlight important ideas and concepts around the TB experience. A list of codes was organized according to community setting. Similar codes were grouped into larger categories and descriptions were generated to capture the richness of the content. Descriptions of categories were evaluated to determine internal consistency within each category and that the categories were distinct from each other (Mayan, 2009). After completing these two rounds of analysis (i.e., initial reading, coding, and categorization), the interviews were revisited to examine similarities and differences between community settings across the Prairie Provinces.

Two challenges were experienced during the analysis process. First, it became apparent that not all provinces or community types were equal in the information that was collected during the interview. This was the largest challenge as certain interviewers diverged from the interview guide or chose to probe on different questions. However, because participants often revealed information in indirect explanations of their TB experience, the data were considered more than sufficient for addressing the research question for this study. A consideration also had to be made in that the number of participants from the remote and isolated reserve participants was a lot smaller than the ones for urban and non-remote reserve participants. While this is important to take into consideration when drawing conclusions, these participants still provided a very important perspective on their own unique TB experience.

Ethical Issues

The *DTT Project* was a large-scale cross-provincial project that required ethical approval from multiple jurisdictions as well as Aboriginal and non-Aboriginal stakeholders. The project followed the Canadian Institutes of Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal Peoples* (CIHR, 2007), and was guided by the PNCs, which were established for the purpose of conducting the study. Institutional level ethics approval was also received at the Universities of Alberta, Saskatchewan, and Manitoba.

A primary ethical concern in conducting secondary qualitative data, as previously stated, is that the data cannot be properly interpreted due to a lack of knowledge and understanding about the context in which the data were originally collected (Gillies & Edwards, 2005; Parry & Mauthner, 2005). To mitigate this ethical issue, an initial literature review was conducted to provide a foundation of understanding to the current Aboriginal TB context as well as enhance the understanding of the health concerns and disparities that Aboriginal peoples face. Furthermore, the *DTT Project* research team that participated firsthand in conducting the research and analyzing the data were used as a principal resource to help fully understand the context in which data were collected.

A secondary ethical consideration is situational ethics and participatory research in working with Aboriginal peoples. Researchers in the *DTT Project* invested a great deal of time in gaining the trust and confidence of the participating communities and Aboriginal participants. It may be argued that if researchers were not present at the beginning of the project (and did not participate in meetings and cultural activities), their analysis may not be accepted. In an attempt to recognize and mitigate this ethical consideration, I immersed myself in fully understanding Aboriginal history, the impact of colonization, the disadvantages Aboriginal peoples face, and Aboriginal peoples historical and current struggles with TB. I also sought the guidance of an Aboriginal Elder with whom I have built a relationship. This Elder is from a high TB incidence community. I offered tobacco to this Elder and turned to her for guidance when needed, thus worked to ensure I participated in the research in a way that honours the traditional practices of Aboriginal peoples.

Rigour

Rigour is important for qualitative research as it enhances trustworthiness. By describing the systematic approach taken in the research project, readers can understand why certain decisions were made and how findings were interpreted. The *DTT Project* research team was made up of physicians, nurses, and researchers that already coded the data through their own iterative data collection and analysis process (with prolonged engagement and peer debriefs) specific to the original *DTT Project* research questions. Through the analysis phase of this study, the *DTT Project* research team was consulted and conferred with over the final codes and categories. The analysis process was documented, which would allow for other individuals to validate the findings in this study. Further to this, the supplementary information used enhances rigour as perspectives could be triangulated and allowed for the data to be situated in the appropriate context. The supplementary documents included the CAFs, which provided concrete evidence for the environments in which the participants were experiencing their TB.

Attention was paid during the sampling phase of the larger *DTT Project* to ensure representativeness of the sample. In qualitative studies, the sample should be drawn from a population that will be the most representative of the people or phenomenon that is being studied (Mays & Pope, 1995). This study did this by recruiting participants who disclosed their Aboriginal identity (i.e., self-identified or having government Aboriginal status), were highly infectious, lived in the Prairie Provinces at the time of diagnosis, and were receiving health services for their TB. Because the participants came from many different Aboriginal backgrounds (e.g., Cree, Dene, Ojibway) and lived in different community settings, a wide range of perspectives on the experience of Aboriginal peoples living with TB was gathered.

Another step to maintaining rigour was evident during the analysis phase where there was the need to address researcher bias by engaging in reflexivity throughout the analysis process (Mays & Pope, 1995). Researchers must reflect on how their own identity and experiences may affect the interpretation of the data and the conclusions that are made. For this reason, I engaged in reflexivity throughout the data analysis process and stated my positionality in the introduction of this thesis. Reflexivity was conducted through the use of journaling and group discussions, which focused on developing initial findings. These discussions included understanding what social connections were and identifying where overlapping themes are best positioned. I was also in communication with the supporting *DTT Project* research team who, by providing insights into my interpretations and contributing additional levels of understanding, enhanced the conclusions that were made. Any codes and categories that were developed that had overlapping implications on the TB experience and therefore could be placed into various chapters within the findings sections were discussed with members from the *DTT Project* research team, which served as an advisory body throughout this research.

CHAPTER 4: INTRODUCTION TO FINDINGS AND DISCUSSIONS

At the outset of this study, the goal was to answer the following research question: what is the TB experience for Aboriginal peoples living in different community settings across the Prairie Provinces? The following chapters introduce the findings and provide a discussion of the findings in relation to relevant literature. The experiences were very personal and often difficult for the participants to share. The findings are presented in a way that attempts to honour these stories. While conducting the analysis of the interviews it became apparent that the participants' TB experience was far reaching and impacted multiple dimensions of participants' lives. The participants came from different communities in three different provinces. It came as no surprise that no two stories were exactly alike; however, participants did describe many similar experiences after becoming infected with TB. In addition to this, there were also noteworthy differences experienced by the participants. The similarities as well as the differences are important to recognize, as there is potential for these experiences to influences current TB policy and practice as well as future research.

The findings from this study demonstrated that as the individual sought a diagnosis and was subsequently treated for TB, various environments and systems were influencing them. The findings and discussions are divided into four chapters that illustrate the various environments that were affected by or ultimately affected the participant becoming infected with TB. The findings and discussions chapters are presented as follows: "'To Have to Look in the Mirror': The Personal Role Individuals Play in their Tuberculosis Experience" (Chapter 5); "'I Could have Lost You': Social Connections and the Tuberculosis Experience" (Chapter 6); "'They're Not Totally Aware of TB': Community and the Tuberculosis Experience" (Chapter 7); and "'I Felt Alone': Isolation and the Tuberculosis Experience" (Chapter 8). Many sub-themes emerged within the overarching themes and are described in each respective chapter. If, in each sub-theme, differences across community settings were identified, they are highlighted and the reasons behind these different TB experiences are explored. Implications for policy and practice are discussed in the concluding chapter.

The individual is naturally at the centre of their TB experience, and for this reason is where the findings chapters begin. The capacity to recognize, acknowledge, and value their own health is where many of the participants began to describe their TB experience. Throughout the chapter on personal influence, the participants spoke about viewing their symptoms as self-inflicted and resigning themselves to accepting their illnesses. After looking at the role of the individual, the next chapter describes the importance of social connections as facilitating the participants to get treatment, and providing strength throughout the process. The participants reflected on the impact their illness had on their families and relationships and expressed fear and guilt over potentially spreading their disease to others. Furthermore, the participants shared the losses they suffered throughout their TB experience in both their relationships and their daily lives.

Moving beyond social connections, the participants reflected upon their experiences of seeking a diagnosis for their symptoms. From being met with multiple misdiagnoses to the importance of having a relationship with a consistent health professional, the heart of this theme is about how access to adequate health services is integral in diagnosing TB. The participants shared their apprehensions with what the overall access to TB information was in their community and how this influenced their own as well as other individuals' perceptions of the illness. Many feared the stigma associated with TB and worried about returning home. This chapter presents the most apparent difference between TB experiences of the participants living in different community settings. Chapter eight examines the impact of TB isolation policies on the TB experience. Patients were kept indoors and disconnected from their families. They shared the emotional impact that receiving TB treatment in isolation had on themselves in being kept alone as well as the disconnect they felt being away from their loved ones.

CHAPTER 5: "TO HAVE TO LOOK IN THE MIRROR": THE PERSONAL ROLE INDIVIDUALS PLAY IN THEIR TUBERCULOSIS EXPERIENCE

The participants in this study shared their deeply personal and often difficult experiences of becoming infected with TB. Interviews typically began with participants reflecting on what an average day was like in their lives prior to being infected with TB and then moved into when they first started to notice that they were unwell. The participants described experiencing various symptoms such as excessive coughing and loss of appetite for substantial periods of time. These symptoms were noted to negatively impact their day-to-day lives, as they got tired quickly, could not finish a meal, and could not fulfill their school or work obligations. The participants' ability to recognize their symptoms as serious and their willingness to get treatment significantly influenced the progression of the disease. When left untreated, TB had detrimental effects on the participants, which was expressed in almost every interview.

Many of the participants shared how they believed that becoming ill was their own fault, attributing symptoms to an unhealthy lifestyle such as "smoking too much," "drinking," or "used to [be doing] drugs." This view ultimately led many to accept their symptoms as being just another part of life. In addition to this, the participants would often state that they were used to being sick and had never viewed themselves as being healthy. Any deterioration of health was accepted because that was how it "was meant to be," and it became evident that participants used this resignation to, and acceptance of illness as a reason to not seek help. Throughout the interviews the participants described their perceived role in becoming infected with TB.

Regardless of where the participants lived at the time of their diagnosis, they blamed themselves for becoming ill, experiencing a deterioration of health, and having a normalized sense of illness. These perspectives are explored through the following two sub-themes (a) attribution of personal responsibility; and (b) the resignation to illness.

Attribution of Personal Responsibility

Across the community settings (urban centre, non-remote, remote and isolated reserve), participants described how they prolonged seeking a diagnosis for deteriorating health. Participants noted that they often did not have the capacity or resources to be able to recognize their symptoms:

> It’s very difficult to see beyond yourself, to speak clearly. My own condition is high blood pressure and lack of short term memory retention so the person who is sick often knows very little their suffering, their scope is limited to, are they chilled, are they bruised, you know, are they in discomfort, their intellectual capacities are not working properly, they can’t see objectively what’s wrong with them often. They need care, but they’re not often the first to communicate about their condition cause they don’t understand it, don’t know how to cope with it, don’t know how to handle what it is they have, and struggle day to day. (Saskatchewan, Urban Centre)

The majority of the participants spoke about how their lifestyle choices hid their symptoms or they believed that their symptoms were a result of their own unhealthy habits (e.g., smoking, drinking, and drug use). Participants often spoke about their previous or current battle with drug and/or alcohol use and how it led them to downplay their symptoms and ignore any consideration that they may be suffering from a more serious illness. One participant noted:

> You know I drank every day almost so I didn’t even notice that it was still with me. I didn’t even know what it was. When I sobered up I started to feel sick again 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 seeking doctors about painkillers. (Alberta, Non-Remote Reserve)

One participant admitted she and her sister were both exhibiting similar symptoms, however, her sister believed that it was probably because of her drinking and smoking and that it was “just her liver or something backing up." Another participant described how he believed his symptoms were the result of drinking or needle use:

> I knew there was something wrong but I didn't know it was TB or something. Maybe it's just because I'm cold or have a hangover. I thought cause I was drinking before I went for a canoe trip...I started thinking, it's maybe because I took that needle or maybe I have something else cause I said I was partying...hanging around with other people like all my buddies. (Saskatchewan, Remote Reserve)

Many of the participants acknowledged that they were experiencing coughing attacks, were short of breath, had a loss of appetite, and experienced extreme weight loss. Even after thinking it may be something as serious as cancer from smoking, participants continued to live with their symptoms; "No I never thought about it. I just thought I was smoking too much. That's what I thought. That's what everybody thought that I was smoking too much…See I thought I had cancer 'cause I smoke a lot." The participants, in acknowledging that their unhealthy lifestyle may be causing them to feel worse, attempted to alter their lifestyle slightly or self-medicate while continuing to put off seeking a diagnosis. One participant described that:

> I'd have to always spit up a lot of sputum and in the morning I just thought it was like my smoker's cough or you know like just a mild cold...I'd take either an Advil or Aspirin and keep on going. (Alberta, Urban Centre)

While another participant stated, "I thought it was just the whiskey...maybe it's too much whiskey on the weekend...cause I did drink lots on the weekends...I thought I'd change whiskies. I started drinking something else minor."

The impact of self-blame and the toll it took on the emotional and psychological well-being of some of the participants was clear. During one interview, a participant had taken a moment to consider how he had acquired TB. He stated, "maybe I did all the wrong things." Another participant, who stated that he had been drinking a lot and was using alcohol to cope with his symptoms, had finally gone to the hospital at the encouragement of his brother. During his interview he reflected back on becoming ill and the situation he was in:

> I'm not scared to say, but I'm disgusted with the situation that I have to be in. I'm an independent person eh. That's why it took [my brother] such a long time to get me to the hospital. I even knew I had to come to the hospital but I just couldn't face myself that I had to. And finally, finally when I started falling down, I had no choice, then I knew, I seen it coming and how come I had to wait till that late. (Alberta, Urban Centre)

When asked what he was most afraid of in going to the hospital he stated, "[t]o have to look in the mirror. To have to look in the mirror and say, 'God damn you, you're no good now.'" Another participant, whose self-esteem had hit a low point, said:

> I'm just starting to feel a little bit better about myself. For a while there I didn't feel I was worth living. I felt like I blew the whole package, you know, like all the gifts the Great Spirit gave me and it's many I've been gifted. Then I wasted them. That's how I felt like not worth living and stuff like that. (Alberta, Urban Centre)

The Resignation to Illness

The resignation to illness was a prominent sub-theme that came out of the interviews as participants described that they viewed their illness as being just another part of life and that it was "just my body shutting down." Many participants shared that they were constantly getting sick throughout their lives and that there was nothing more that could be done. Participants struggled to define good health, what a healthy individual is, and/or identify a healthy person in their community. This lack of understanding of good health contributed to many participants' decisions to delay seeking health services. Resignation to illness was described by one participant as giving up, and coming to terms with the fact that she was probably dying:

> I slept basically, I napped all summer long and as I said into the deep part of fall I decided that I was dying and that whatever it was…I resigned myself to that fact. I thought "Well either, whatever I have will remit, go into remission or it'll total me off you know, kill me"…and I didn't choose to do anything about it. I didn't know what I had but I was really sick and so basically what I did was get out of bed and crawl to the

> computer and do as much work as I could then go back to bed. (Saskatchewan, Urban Centre)

This belief that the illness had taken over, that the body was shutting down, and that death was imminent was further described by a participant who also began showing more extreme signs of TB, had lost a lot of weight and was having night sweats, but was not alarmed by the severity of the issue. He was asked, "So when you were sick with TB you thought it was the same thing as always?" To this he replied, "Yah that's what I thought." The participants were resigned to illness, it was just another part of life, TB symptoms were not seen as unusual, "there was no fear, there was just another sickness." Participants described feeling as though sickness was inevitable and that there was nothing that they could have done to prevent it. A participant was asked, "how does that make you feel when you have TB?" He replied, "I guess it's the way it was meant to be...That's the way it's probably written." Many participants described how they had not been healthy to begin with and therefore any new symptoms were just accepted. One participant described, "I was never a strong person anyway. I was always sick as a child." An elderly participant conceded that she was always going to be sick and that the TB was inevitable; "I probably just got it because I'm a sick woman all the time. Just one thing after another comes out of my body." A participant expressed being fed up with her ongoing health struggles: "I guess I'm so tired of pills. I'm so tired of being that sick person. I don't wanna be a sick person any more. I wanna be happy at least once, one day." The resignation to illness was experienced even among the young generations as one male youth, who was still in high school when he became sick with TB stated, "that's how it is…It's just like that. I figure if I'm sick, I'm sick, that's it."

Two participants in the study expressed that they believed people in general do not try to get better; “nowadays I think people accept sickness” and “some people just don’t go for the treatments or the medical help that they need to get themselves better.” One participant described this resignation to illness as individuals giving up; “[a] lot of people give up on and give up hope and I’ve seen lots of people give up hope.” Another participant was asked why he believed Aboriginal peoples were continuing to get TB? And to this he stated, “I think nothing of it. I think just like the wind it comes and goes, I guess.”

Discussion: The Personal Role Individuals Play in their Tuberculosis Experience

This chapter focuses on two important personal factors that influence the TB experience: participants’ beliefs that it was their own responsibility for getting sick, and their resignation to illness. It is apparent that regardless of whether participants lived in an urban centre or on a non-remote, remote, or isolated reserve across the Prairie Provinces, when they were experiencing their symptoms, they took on an incredible burden of self-blame and/or they initially failed to be scared by the symptoms; illness was commonplace. Participants stated they had often lived for months with the symptoms, resulting in more severe health issues, which then finally took them to the hospital.

The attribution of personal responsibility was a key finding in understanding why the participants in this study did not seek help sooner. It was expressed by participants that many of the TB symptoms were masked by alcohol and/or drug use. Previous studies have identified that individuals play an important role in their own TB experience as they often downplay symptoms and/or that their unhealthy lifestyle choices impact treatment delay (Kiwuwa, Charles, & Harriet, 2005; Macdonald et al., 2010). Wynne, Richter, Banura, and Kipp (2014) sought to understand individual factors that influence diagnosis delays and found that TB patients commonly attempted to ignore early symptoms and self-medicate.

For the Aboriginal peoples who have a history of drug and alcohol use, the notion that they are to blame for the illnesses that impact their life is not altogether unexpected. The participant who was quoted above as being afraid to look in the mirror because of the poor state he had allowed himself to get to and believing that "you're no good now" shines a very important light on the impact disease has on an individual. The literature on attributional styles is important to consider with regards to being diagnosed with TB. As Abramson, Seligman, and Teasdale (1978) noted, when individuals who are faced with negative life events internalize the causes and place the locus of control on themselves, they are more likely to have a depressive reaction as was the case with some of the participants in this study. However, no studies were found that looked at self-blaming attributes among TB patients, and there is limited literature specifically looking at the causes of self-blaming attitudes for illnesses among Aboriginal peoples.

Illness was just another part of life for participants, possibly their fate, and was generally accepted. These findings are consistent with other research that has indicated that among Aboriginal peoples a resignation to illness is commonplace (Heil & MacDonald, 2008; McMullin et al., 2012; Stanner, 1963). McMullin et al. found that among a group of Aboriginal participants, there was an overwhelming sense of apathy towards TB and its continued stronghold on Aboriginal communities. In a personal reflection by Gruen and Yee (2005), two community doctors working in a remote Aboriginal community in Australia, they noted that there was a large "sufferance" (p.538) to illness. This was found to be both "perplexing and disturbing" (p. 539) to the doctors who witnessed families tolerating illnesses or being desensitized to illness in general. Stanner (1963) referred to this as Aboriginal peoples' assent to life's terms. Heil and MacDonald similarly found that among Aboriginal peoples in Australia, illness is expected along with all other aspects of human life. Heil and MacDonald argue that Aboriginal peoples view life as outside of their control, and that because life is unpredictable, worrying about the future is unnecessary. As Heil and MacDonald further note, Aboriginal peoples experience health in terms of their ability to perform everyday tasks. Therefore, Aboriginal peoples diagnosed with diseases that develop slowly over a long period of time (such as TB) adapt to not feeling well and get used to living a certain way.

It was often not until participants could no longer perform their everyday tasks that they began to question their health. Many of the participants in this study expressed acceptance of their present circumstances and a resignation to being sick. When participants started falling down and/or coughing up blood they finally sought treatment. Participants often did not go to the hospital when the initial symptoms of coughing and a loss of energy were first presented. These findings are consistent with Heil and MacDonald who found that Aboriginal peoples are more likely to go to the hospital with an emergency than go see a doctor for more minor presenting symptoms. This was identified as being because of the belief that "tomorrow will take care of itself" (p. 307) and that if there is a crisis, there will be individuals in their life who will provide the necessary support.

Within Canada, Aboriginal peoples carry a large burden of diseases (e.g., TB, HIV). The participants in this study had expressed disappointment and sadness over living with their illness for so long and not believing it was more serious. It was identified by one participant that the resignation to illness had become a larger community issue. This negative community level experience is sustained by environments that exploit the notion that Aboriginal peoples are of a lower social standing, which is promoted through institutionalized and then internalized racism (Chavez, Duran, Baker, Avila, & Wallerstein, 2008). The exploitation and the proliferation of negative views of Aboriginal peoples are having deep and longstanding psychological impacts including becoming accustomed to this idea of always being sick. Anthropologists have long argued that Aboriginal peoples' health and well-being are not measured by personal health but are contingent on social dynamics and kinship networks (Myers, 1986; Sansom, 1980). Within this study, participants acknowledged that they were unable to define or identify a healthy person within their social networks, which also highlights a larger community issue that can continue to negatively influence high TB rates. This will be further explored in Chapter eight.

It is evident in these findings that regardless of where the Aboriginal participants lived, they experienced very negative personal turmoil that resulted in them being unable to identify or appreciate their illness. The ability to appreciate deteriorations of health, understand that presenting symptoms are serious, and have the motivation to seek a diagnosis are important factors in preventing and controlling the spread of TB. If Aboriginal peoples continue to attribute the locus of control for TB internally, have a normalized sense of illness and delay diagnosis, the TB rates will continue to grow and so too will the large disparities between the health of Aboriginal peoples compared to non-Aboriginal Canadians. They will also experience greater health risks and will ultimately be required to remain in hospital for longer periods of time while their body recovers. This study provides a foundation for future research into understanding the impacts of self-blame and understanding how individuals definitions or interpretations of health can impact their willingness to seek medical attention.

CHAPTER 6: “I COULD HAVE LOST YOU”: SOCIAL CONNECTIONS AND THE TUBERCULOSIS EXPERIENCE

The previous chapter outlines how participants were unable to fully recognize and acknowledge their symptoms as being serious, believed their lifestyle choices were the cause of their symptoms, and had a normalized perception of illness. As participants told their stories of first experiencing their symptoms, they highlighted that because they did not appreciate how serious their symptoms were, it often took another person to acknowledge and push them to seek a diagnosis and treatment. It became apparent that external people and the social connections the participants had were important parts of the TB experience. From first appreciating that participants were ill to helping them navigate health services, the social connections that participants described were integral in providing support. It was further acknowledged that social connections continued to impact the TB experience until the very end when participants were motivated to remain in isolation and get the treatment they needed to get better for their loved ones.

While social connections positively influenced the TB experience, participants also reflected on the negative impact TB had on these very same connections. Participants experienced feelings of fear and guilt over spreading their illness to those they loved. In addition to this, their deterioration in health resulted in participants experiencing significant losses in their lives, such as losing employment, and the breakdown of close relationships.

All of the participants had varying social connectedness which was experienced differently throughout the community settings. This chapter describes these findings through the following sub-themes: (a) encouragement to seek a diagnosis; (b) strength from and strengthening family, (c) fear and guilt; and (d) loss. In the sub-themes of (a) encouragement to seek a diagnosis and (d) loss, the urban participants who experienced a lack of social connections had somewhat different TB experiences.

Encouragement to Seek a Diagnosis

Due to the participants' inability to fully recognize their symptoms as being a serious illness and their normalization of illness (as previously discussed), social connections, primarily family, served an important role in participants seeking a diagnosis. While the individual(s) that played this role varied (e.g., mother, brother, husband, friend), the importance of having these connections was highlighted by participants living in each community setting across the Prairie Provinces. From encouraging phone calls from loved ones telling the participants to go to the hospital to actually taking them, social connections proved to be an invaluable source of motivation that pushed participants to seek a diagnosis.

As it was stated in the previous chapter, the inability to recognize the severity of TB was expressed by a participant who said, "you don't see yourself at the time." This statement draws attention to the importance of an external perspective to help participants acknowledge their deteriorating health. Participants described being pushed by family members, who became concerned over how sick they were, to seek help, but often being resistant to do so:

> When I was getting sick at my brother's place, he says "you're sick man. Look at you. You're dying on me....let's go to the hospital." Then he recruited [my other brother] to go on his side so now they're ganging up on me. "Come on. You gotta go there." "Ah come on you guys, quit bugging me now" and then I kept drinking. Then I started to pass out and stuff like that. That's where I noticed that I'm pretty sick. [My brother] said "sometimes you just look like it's not you. Your skin is grey" and I said "ya well I'll go see a doctor." (Alberta, Urban Centre)

Family members or close friends were critical witnesses of the progression of the disease. One participant had been living with his sister who told him "look at yourself." He had been unable to see how sick he had gotten and was finally pushed to seek professional help.

Even when participants did notice their failing health, they needed extra support and encouragement to seek a diagnosis. A participant admitted that she had been feeling sick for quite some time but it wasn't until a day when she was together with many of her family members when they finally had to say "phone the ambulance...look you're breathing again fast. I'm gonna phone the ambulance." A husband who was present during his wife's interview described seeing her health deteriorate, "she coughs all the time." The husband had previously experienced TB and knew that it was possible she could have it too. It was through his constant encouragement that she finally went to the hospital and sought medical attention. A young participant talked about his mom becoming concerned over how sick he had become and stated that he needed to go and see the community nurse:

> My mom knew that something was wrong right away when I was just going to sleep. There was just bags underneath my eyes and she told the TB nurse and they took me for an X-ray and they found out that I had the TB. (Saskatchewan, Isolated Reserve)

It is important to note that a family member did not necessarily need to be in close proximity to pressure participants to seek a diagnosis:

> My mom said, "Come to Edmonton. Come I'll take you to a doctors." She goes to a medi-centre on the south side and she said, "I'll take you to these doctors, they'll help you, they'll treat you the way you're supposed to be treated" she said, "'cause that's what I did." She said, "I had to come to Edmonton and see real doctors and they prescribed whatever they had to, to get me better." (Alberta, Non-Remote Reserve)

One participant had a particularly difficult time with her illness. She stated that she would wake up "just drenched in sweat...I couldn't breathe. I couldn't even take a deep breath...my weight went way down where I felt like I'd scratch my back I could feel my rib bones." Her family was pressuring her to go to the hospital, as they had seen she was getting very sick, but she stated that she had been in the process of moving and did not have time to go to the hospital.

She viewed her poor health as an annoyance that was getting in the way of her being able to provide for her family:

> My mom kept coming to me every day. She even came on her knees beside me crying to go see the doctor and I kept saying, "No. Let me move. Let me get settled"...I was just mad that they were making me do this. I didn't want to. They were making me do this but I didn't wanna put my oldest sister through that cause she's a diabetic. I didn't wanna put her through that to come get me while she was working. She was gonna get off work and so I agreed for my other sister and my mom to take me in that day and so they brought my daughter home. They picked her up at school. They already had this plan so I said okay. And so I go with my three girls, my oldest daughter and my two youngest ones at home there and I didn't wanna kiss my kids cause I said, "I'm coming back" I said and I wasn't gonna take, I didn't take no clothes, nothing. "I'm coming home. I'm not gonna kiss 'em." I told my mom that. I was kinda mad. So we left and all the way there they were quiet and cause I was mad, I didn't wanna talk to them. Like they were making me do this. They were getting the other family members involved but at the time I didn't know my other sisters and brother were, you know, pushing my mom and my sister to do this for me. (Saskatchewan, Urban Centre)

After being admitted to the hospital, the doctors made her realize that her family had saved her life:

> 'why are you crying? You know your mom saved your life. Thank your mom and your sister. If you waited one more week like you're telling your mom 'give me one more' you woulda came in, in an ambulance. You woulda had a collapsed lung. That's how bad that infection is in your lung.' My left lung here. He said 'if you'd waited one more week you would have been in a coma or had a collapsed lung. Thank your mom. Don't be angry at your mom.' (Saskatchewan, Urban Centre)

In contrast to the experiences highlighted above, some of the urban participants had moved away from their home communities, lost family members, and had little contact with the ones remaining. Yet the role of social connections was still important for these participants as others in their lives, beyond family members, could appreciate their deterioration in health. One of the participants, who had experienced periods of homelessness, built a connection with a man he met in a shelter and it was this friend who inevitably acknowledged that the participants' illness was progressing:

> What alerted him he said was I wasn't even eating like I'm a really heavy eater and this place we were at we like roast beef, mashed potatoes, like it was a great meal and I could only eat little bits and pieces. I was shivering and he said I looked really pale so he got kinda scared for me and he's never seen me like that before and I never felt like that before having the chill. Like I was drinking hot coffee and still was making me colder and then I felt a little bit of sweats and off and on and that's when he phoned the ambulance. (Alberta, Urban Centre)

Another urban participant acknowledged that she did not see herself as sick, "[it] was my friends [who] noticed that I was losing a little bit of weight…like around my eyes and everything but I never noticed it." Having a relationship with a community service provider was also noted to be important among some of the urban participants who did not have strong social connections. A homeless participant focused on his relationship with a city police officer who had become friendly with him and other people living on the street. The police officer had remarked on his deterioration of health but was consistently met with the participants' unwillingness to seek further treatment. With few options, the police officer issued him a ticket to get him off the street and out of the cold for the night. He attributed this act to ultimately saving his life as it pushed him to want to finally get a proper diagnosis.

While many urban participants had family members or had developed strong connections with other individuals who pushed them to seek treatment, there were also many who lacked that foundational support and were socially isolated. This gap in social relationships led many of the participants to go for extended periods of time without seeking a diagnosis. An urban participant did not have any family in the city in which she lived and did not become concerned about her health until she was coughing up blood and feeling faint. This finally led her to ask a neighbour to call her an ambulance. One participant went to the same walk-in clinic four times under her own volition after waiting three months while her health got worse and worse. Another participant described how he lacked insight into his own illness. With the rapid progression of

TB he had lost energy and motivation and no longer “felt like doing anything.” He was ultimately brought into the hospital in an ambulance as the TB had taken over his body. He did not identify who called the ambulance for him.

Strength From and Strengthening Family

Participants from across the Prairie Provinces and community settings viewed their family, and other important relationships highlighted above, as sources of strength to keep going and to get better. The interviews were conducted with the participants early in their TB treatment, and they were experiencing a lot of sadness over being isolated and away from their loved ones. However, their loved ones proved to be the reason they wanted to stay in treatment and get better. Participants described drawing their biggest strength from their children and grandchildren and expressed their desire to stay in treatment for reasons such as, they “didn’t want to make [my kids] sick,” “my kids...Like sometimes I feel like giving up but then what?” and “I keep going for my baby.” A mother expressed her desire to stay alive and get better for her children:

> At times I feel like killing myself but it, it doesn’t work...Cause I don’t want it to work...I think about my kids. Especially my kids, like if I hear them it makes me happy, keeps me going...If they’re not here then I feel worse. (Saskatchewan, Isolated Reserve)

A grandmother was asked, “what gives you strength to go on,” to which she replied, “making sure the kids are all right.” Another grandmother used her time in treatment to think about her grandchildren, as she came to realize her previous life choices and addiction issues had negatively impacted her relationship with her own children. However, since becoming sick, she stated that she wanted to make it up to her children and get better for her grandchildren:

> Before my grandchildren came along, my three children, I used to put the bottle ahead of them, you know. Oh I couldn’t wait ‘til the weekend rolled around so I could go party and leave them and, you know, that sort of stuff…Then right now I’m making it up to

> [my daughter] with her children, you know. I didn't look at it like that before, but no I don't want to make the same mistakes. (Manitoba, Isolated Reserve)

She laughed about the constant security watching her door, "I feel like people are watching me and waiting for me to run and with my handicap, I don't think I can run very far. I wouldn't think of it anyway. I wanna get well for my grandchildren." Even when parents and grandparents had not seen their loved ones in a number of years, they viewed their children and grandchildren as a source of strength. One of the participants, when asked what gives him strength, stated:

> What gives me strength is my family, you know. I love my family...I like to help them out, it gives me strength, kids, I got kids but I haven't seen in a while. But they give me strength. It makes me wanna live more eh, do things more. Give me strength. (Alberta, Non-Remote Reserve)

The notion of getting better for immediate family was prominent, but it was also noted by the participants that there was a need to get better for others in general. Participants shared that they wanted more people to hear their story to raise awareness about TB. One man stated that he wanted to get better, not only for his children and grandchildren, but for others, as doing this would give him "encouragement and make me feel worthwhile." He went on to explain:

> I get thinking about this eh and I think it, just to see people every day...I'm lucky. My children are grown up. That's pretty well if I wanna do anything useful with the rest of my life that's to get in here and try and get healthy again...I'm gonna seek out the best I can get for myself...It's for myself and for the people I associate with, my children, my grandchildren. Nice little guys. (Alberta, Urban Centre)

Another man expressed a similar sentiment:

> What's the point in carrying it...Once you get that sickness, from my experience, it hurts. If you don't help yourself, giving yourself to doctors that can help you, then you're in pain, you're gonna die. You don't wanna spread disease more to innocent people, right. (Alberta, Urban Centre)

Participants often felt that going through treatment and being separated from their family was extremely difficult. However, the TB experience was also said to have strengthened relationships. The mother from Saskatchewan, who was in the process of moving and did not want to be burdened with going to the hospital, had also experienced a breakdown in her relationship. Her husband had left her because “I was always angry cause instead of showing the pain I showed anger a lot.” However, following her diagnosis and returning home to receive treatment she and her husband reunited:

> Now that he knows more about it, he’s not afraid of it, nothing. We’re back to the way we were when we’d hold hands and he tells me every day now he loves me and cause when he came back, and we’d talk, and he’d talk to the doctors, when I’d go to my appointments and he cries now too like “I’m sorry. I could have lost you.” (Saskatchewan, Urban Centre)

One of the participants decided to share her diagnosis with her sister who had also experienced TB when she was younger. The participant felt that her relationship with her sister was strengthened because of their ability to share their experiences with TB. Her sister supported her as she went through treatment by bringing her traditional Aboriginal medicine, and visiting her at the hospital regularly.

Another important relationship that was strengthened was especially spoken about by the younger participants who, while they were receiving treatment became closer with their parents. A male youth from Manitoba stated that he passed his time in the hospital talking to his mother on the phone and stated that he gets “strength from my mom.” Many participants described experiencing hardships and personal conflicts even before becoming sick with TB. A young participant had been bullied by other girls in her community and attempted suicide twice by overdosing on prescription pills. She stated that she had felt alone and that she could not talk to anyone about what she was going through. After being admitted to the hospital with TB, she stated that she and her mother:

> Became friends ever since [being in the hospital]…’cause I never talked with her…It’s nice [I was] scared. At first I didn’t want to talk about it…then I just told myself I should,

> I should, so I did…and she told me about her teenage life. It compared to mine. (Manitoba, Isolated Reserve)

The TB diagnosis and ending up in the hospital enabled the participant to begin talking with her mom. She stated that her mom had grown up with TB in her family and they began to share more about their lives and as a result, strengthened their bond.

Fear and Guilt

Although the participants with strong social connections noted the positive outcomes of receiving strength and encouragement from their family members, many also expressed experiencing extreme feelings of fear and guilt that they had spread the disease to their family members. Fear and guilt were emotions expressed by the participants with social connections from every community setting across the Prairie Provinces. These emotions permeated through every phase of the TB experience from being first infected to receiving treatment. Many participants, who had been living with other family members for extensive periods of time, while unknowingly being infected with TB, had potentially exposed their loved ones to the disease. One participant stated, "I'm scared, having TB and [HIV], I'm scared what it's gonna do to me and I don't want to pass it in any way to my family, so that's where I'm sitting right now." A participant expressed anger and guilt over living with his sister and her children while having TB:

> I'd been living at my sisters all winter and maybe I passed it on to them. She's got kids in the house eh, and the people I contact with, you know, living with the TB all along for 8 months that's a long time being around people...Like what about maybe passed it on you know. It's really, really kind of hard in the mind when you think about it. (Alberta, Non-Remote Reserve)

Another participant had found out that he had been infected with TB for months. After finally receiving a TB diagnosis, he was told that he needed to isolate himself, ''[w]hat do you mean isolate myself? I've been coughing this thing for, you know, here is in my family, especially my mom. I'm the only one that takes care of her."

Some participants expressed feeling guilty about causing shame and embarrassment to their family. A father feared that community members would find out about his TB and tease his children: "they'll probably get a bad name to themselves [for dad having TB] and kids will probably tease them." Due to their fear of spreading TB, many participants began to withdraw, not only from their community but from their loved ones as well, especially parents and grandparents. One participant stated that she was scared of giving her son TB and because of this fear she didn't "carry him that much." A grandmother also tried to separate herself from her grandchildren: "I try not to be close to them…I stay away." Another grandmother refused to eat with her grandchildren because she believed she could pass on her TB by sharing cups and plates. Even though the participants were often still receiving treatment in isolation at the hospital, they expressed fear over returning home and potentially infecting their loved ones. A participant who had been the primary caregiver to her children while her husband worked, expressed sadness about being infected with TB, as she feared she would pass on her disease. "My family, they are always there to support me. My life revolves around my family. I try to make it easier for them. I don't want to pass on this disease." At this point in the interview the participant became quite emotional. She was very overwhelmed about the way she tried to protect her family and that she was now forced to be away from them.

Loss

Loss permeated many points throughout the TB experience. As previously stated, participants lived with their TB symptoms for lengthy periods of time; the participants described how TB negatively impacted many aspects of their lives in addition to their physical health.

Regardless of where the participants lived, TB caused a breakdown in relationships and left many without a job. However, where their stories differed was for the urban participants who lived alone, relied on social assistance to pay for their housing, and/or who lived in boarding houses and had nowhere to return to after completing treatment. The on-reserve participants also experienced their own unique losses related to their ability to hunt and fish. Entire communities were negatively affected when a contributing member of their community was sick and receiving treatment. One participant shared how he had been extensively involved in his community by helping to run programs and organize events. With his departure for treatment, some of these activities were no longer being performed.

While many participants spoke about how their family members rallied around them during their TB diagnosis and treatment, there were also a number of participants who spoke about how their family began to fall apart. The Saskatchewan mother who had lost her husband after becoming ill and whose family pushed her to seek a diagnosis, had been experiencing a great deal of anger and frustration over becoming sick. Even though she and her husband reconciled, her daughter ended up leaving because she could not handle seeing her mother so sick while she was being treated at home:

> When I got sick she couldn’t stay with me. We actually ended up arguing and after I got out of the hospital she ended up leaving. She couldn’t take the way I looked or the way I was always in bed and sleeping. She couldn’t handle that. She didn’t wanna see me that way. She actually ran away for about a week. And then she experienced marijuana and alcohol during that time. (Saskatchewan, Urban Centre)

Tuberculosis further compromised some already fragile family situations. A participant, who had been working with Child Welfare to get her children back in her care, believed that her social worker used her illness as a reason for keeping her children under the guardianship of the government and not allowing her to see them:

> Because of the viruses Child Welfare is telling me “no, I can’t be around my kids” and I don’t want to accept that because I love my kids. They’re taken till they are 18. I don’t know what more they want. (Alberta, Non-Remote Reserve)

The negative impact of TB on relationships was also extended into the participants’ daily lives as they began to isolate themselves, push others away, lose self-esteem, and in many cases lose their jobs. A participant had been a chuck wagon racer during the summer for a number of years. After falling ill he had lost a lot of weight and energy, felt insecure about his ability to form relationships with women, and began to feel weak while working.

> Before I knew I was sick or before the doctors told me how sick I was, I started withdrawing, I started being insecure, less sure of myself. Around the horses fear was coming in. I thought I was lazy but I was tired. I see now I was tired and because of the weight loss I was shying away, I didn’t feel good about myself and I felt weak therefore I started acting weak. Then I felt intimidated by other men and even women when I’d see them out working and then I’d go to work and some days I just couldn’t last all day so I’d come up with an excuse. I couldn’t tell the truth that I was tired so I started to lie. The insecurities I was talking about, economic insecurities, and then my relationships, I’m a bachelor but I still have relationships and the weight loss I became self-conscious. I started looking at my body as who I was, not the person I am inside. I’d have certain girlfriends, lady friends that knew who I was but yet I’d push them away because I started losing weight. (Saskatchewan, Non-Remote Reserve)

He ultimately had to step away from his job and struggled again with alcoholism that he had, for a long time, put to rest. Another participant shared his own experience with TB and the far-reaching ripple effects the illness had on his life:

> It went downhill. I got sick from the TB. I didn’t know. They misdiagnosed me, right. I started losing weight and I couldn’t sleep. You know a lot of factors hey and going back to the hospital again and they just say the same thing. You know, they didn’t know. They couldn’t figure it out so I went back to work and I told [them] I couldn’t work anymore. I’m too sick. So he said “okay take some time off” and I was going broke eh. So I had to go back to work and I couldn’t work so I just told him I can’t do it so they let me go. They said “we don’t need your services anymore.” So after that I just became more ill and more sick and couldn’t find any work. Losing weight. Couldn’t figure it out and hospital didn’t know what it was. Next thing you know I was out of my apartment, had no money eh. Welfare wouldn’t help. Said I was able to work. Said “you know, colds can’t stop you from working” you know. So okay fine and I didn’t know what I had. (Manitoba, Urban Centre)

Participants experienced misdiagnoses that resulted in more and an exacerbation of the losses in their lives. The full extent of how misdiagnoses impacted participants will be further elaborated on in the following chapter; however, it is important to note that misdiagnoses played a significant role in magnifying their experiences of loss.

The loss of employment was an event that resonated with many of the participants. For example, a firefighter, who had held his job for 20 years, was no longer able to perform his duties or pass his physical exam due to his TB symptoms. His job had been a large source of pride and he noted the loss to be very difficult for his family. Another participant who had to quit her job because she had become extremely tired and had no energy throughout the day stated, “[I was] lonely. I’d be sitting at the window watching people walk by full of energy, you know. I just wish I was feeling like that again.” Participants further expressed frustration over being forced to leave their jobs and their families for a period of time as they were the main source of income and sometimes even food (through hunting and fishing), but they had often become “too weak” and just “couldn’t take it...can’t do it anymore.”

The loss of housing was experienced by many of the urban participants who lived alone and when they could no longer work, they could no longer afford to pay their rent. Others spoke about receiving support through social assistance to stay in boarding facilities or subsidized housing, but when they were no longer living at their accommodations, their space was given to someone else. An urban participant’s social worker revoked her rent payment for her room in a boarding house after the participant was admitted to the hospital. Since she was no longer staying in the boarding house, all of her belongings were removed and she stated that she would have to “start over” after being released from hospital.

Discussion: The Impact of Social Connections on the Tuberculosis Experience

The relationship between social connections and the TB experience was apparent throughout participants' stories. Regardless of where the participants lived when becoming sick with TB, social connections proved to be an extremely important part of their lives as they navigated their illness. Participants were encouraged to seek treatment, received strength from and experienced a strength in family, felt guilt and fear over potentially infecting their loved ones, and experienced a great deal of loss. Where the TB experience differed for the participants was when they lived in urban community settings and lacked a strong social network. A comparison across the sub-themes is displayed in Table 3. Many urban participants expressed not having close family members to notice their deterioration of health. Therefore, they often relied on service providers and individuals they had built a relationship with on the streets to push them to seek a diagnosis. When there was no one close to them, they often went to the hospital only when the TB had taken over to such a great extent that they were no longer able to cope day-to-day. In addition, many of the participants from across the community settings lost their jobs and were unable to provide for themselves and for their families; however, the final noteworthy difference experienced by participants living in urban centres who lacked a social connection and, as a result of the TB, were no longer able to work, pay rent, and/or stay in their homes. Some of the participants were being provided with social assistance for their accommodations and when they were admitted to the hospital, their living situation was no longer available. They were not sure where they were going to go after finishing the isolation phase of their treatment.

Table 3

Social Connections Sub-theme Comparisons across Communities

<table>
<thead>
<tr><th>Sub-theme</th><th>Urban Centre</th><th>Non-Remote Reserve</th><th>Remote Reserve</th><th>Isolated Reserve</th></tr>
</thead>
<tbody>
<tr><td>Encouragement to Seek a Diagnosis</td><td colspan="4">Participants had social connections with individuals who observed their health deteriorating and encouraged them to seek a diagnosis.</td></tr>
<tr><td></td><td>Participants who lacked social connections relied on service providers or had no one to encourage seeking a diagnosis.</td><td></td><td></td><td></td></tr>
<tr><td>Strength from and Strengthening Family</td><td colspan="4">Participants received strength from their family to stay in treatment and family connections were made stronger.</td></tr>
<tr><td>Fear and Guilt</td><td colspan="4">Participants experienced fear over being diagnosed with TB and worried about spreading their illness to others.</td></tr>
<tr><td>Loss</td><td colspan="4">Participants experienced losses in their lives from acquiring TB including losing their jobs and important relationships in their lives.</td></tr>
<tr><td></td><td>Participants who lacked social connections often lived alone, relied on social assistance to house them, and/or lived in boarding rooms. They could not pay rent or lost their accommodations after entering the hospital.</td><td colspan="3">On-reserve participants experienced a loss in their ability to hunt and fish.</td></tr>
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The importance of having strong social connections during times of illness is not unique to experiencing TB or just for Aboriginal peoples. Previous research has shown that family is viewed as a positive system, which supports those who are ill (Brashers, Neidig, & Goldsmith, 2004; Ell, 1996). Although participants initially resisted seeking medical help, through continued family pressure, the participants finally sought a diagnosis. In a study conducted by Chard (2009) with TB infected women in Uganda, it was found that “treatment seeking is a social process” (p.266) and that because TB often presents as nothing more than a cough, the participants relied on family and friends for other interpretations and advice. Even when the participants in Chard’s study rejected treatment advice from family members, they were still instrumental in providing emotional, financial, and physical support. Also similar to the findings in this study, Siminoff (2013) found that social connections have implications for diagnosis and treatment as family members and caregivers influence health related decisions. The family has a large influence on the patient’s ability to see their own illness, recognize it as being serious, and communicate effectively with medical providers.

Participants who lived in urban settings and did not have strong family supports relied on connections with service providers or individuals they became friends with on the street. Inner-city participants in Marra, Marra, Palepu, Cox, and Fitzgerald’s (2004) study shared that they lacked a strong support network and therefore did not share their TB experience with anyone. Macdonald et al. (2010) also found that among their Aboriginal participants, their connections to the urban Native Friendship Centre and the positive relationships they had with the service providers there encouraged them to seek medical help. The individual’s willingness to seek a diagnosis was promoted by the more they had interactions with and access to social connections

(Macdonald et al., 2010; Marra et al., 2004). The findings in this study support other research (e.g., Maulik, Eaton, & Bradshaw, 2009) that has found that access to health services was directly linked with the frequency of social interactions. Participants who had no connections at all were left to navigate their illness alone. These social connections are important to consider when understanding the TB experience as not all individuals have the same support networks, especially in urban settings.

Other researchers have found that family ties are strengthened when a patient is diagnosed with TB and family members provide support throughout the process, resulting in a positive impact on their treatment experience (e.g., Hansel, Wu, Chang, & Diette, 2004). In addition, research has shown that patients favour having family involvement in their health care (Botelho, Lue, & Fiscella, 1996). The participants in the current study often voiced concerns over being diagnosed with TB and only wanting to share their diagnosis with family and close friends for fear of being treated poorly by others. These findings relate to other research (Edwards & Lopez, 2006; Ushie & Jegede, 2012) that shows that family is important in providing emotional support when a patient is dealing with a stigma related illness as it helps to mitigate the impact of fear and guilt.

However, in spite of family support, the experience of fear and guilt were still present in this study. Parents and grandparents were afraid to hold their own children, share food with loved ones, and worried about the burden receiving treatment away from home placed on their families. The findings from this study are similar to those that look at the quality of life for patients who suffer from a stigmatized illness (e.g., Dhuria, Sharma, & Ingle, 2008; Hansel et al., 2004). Similar to the current study, Dhuria et al. (2008) and Hansel et al. (2004) found that TB negatively impacts quality of life in terms of social functioning as patients score very low on psychological and social domains. Hansel et al. conducted focus groups among health professionals and patients and found that social functioning and role functioning were greatly diminished for TB patients. Participants noted that they experienced a loss of friends, and because they were afraid of passing the disease on and ashamed of their diagnosis, decreased the time they spent interacting with close friends and family. Eastwood and Van Hill (2004) found in their study in West Africa that, because TB was viewed as a disease that was a result of extra-marital affairs, it had an impact on marital relationships. This does not align with the current study; however, participants often became agitated and difficult to be around before their diagnosis, which altered the dynamics of the marital relationship.

Throughout participants' illness and while struggling with their symptoms, they noted that they often experienced a loss of self-esteem and a loss of close relationships. Having an illness takes a large toll on families as patients fight to get better and come to terms with their diagnosis, as was witnessed when a woman's husband left her and her daughter ran away from home, and a man pushed away the women closest to him. The losses participants experienced in this study did not end at their ability to maintain relationships but also affected their level of energy and their ability to perform regular household chores, provide for their families, or maintain their employment. Similar to the findings in this study, international studies have found that TB has negative effects on the socioeconomic status of patients; they have difficulty maintaining a well-paid employment and many employers are unwilling to hire TB infected individuals (Brand & Clairborn, 1976; Johansson, Diwan, & Huong, Ahlberg, 1996; Khan, Walley, Newell, & Imdad, 2000; Rajeswari et al, 1999). The inability to maintain work caused a great deal of distress among some of the participants, which is similar to findings in other research (Needham, Godfrey-Faussett, & Foster, 1998; Sagbakken, Frich, & Bjune, 2008).

The findings from this study add to current research as it brings awareness to how social connections factor into Aboriginal peoples' experiences when they are infected with TB. The importance of having family or other close relationships was evident from initial infection all the way through to being treated for TB. The impact of being infected with TB on emotional well-being cannot be emphasized enough. Even though the participants were going through treatment, they continued to be fearful about spreading TB to others. When parents and grandparents thought about returning home, they expressed that they would not want to go near their loved ones. This demonstrates a clear discrepancy between how TB information is being presented by health professionals and participants' understanding about transmission. Because of the importance of family in the illness experience, this gap brings to light the importance of educating those closest to the patients about TB, what it is, and how it can be spread, which could eventually mitigate some of the losses that come as a result of the illness.

The urban participants who lacked strong family connections bring to light another area of concern for health professionals and policy decision making. If individuals do not have a social network, and there is no one to notice their deterioration in health, TB has more opportunity to cause extensive damage to their body, increasing the emotional and physical impact of the disease and the length of hospitalization time. This group of participants experienced greater losses as they could either no longer afford to make their rent payments or their social assistance for housing had been cut off. This would typically not be experienced by Aboriginal peoples living on-reserve as their housing is provided by the band and provides an important area of future consideration for health and community services providers.

CHAPTER 7: “THEY’RE NOT TOTALLY AWARE OF TB”: COMMUNITY AND THE TUBERCULOSIS EXPERIENCE

The community has the potential to serve as an integral point of access to health services, general health information, and to be a safe and secure place for individuals with TB to live without fear of being treated differently. However, when participants shared their TB stories, it became clear that where they lived affected many different aspects of their experience, and not in entirely positive ways. As a reminder, the term *community* is used to define where the participants lived at the time of their diagnosis (e.g., urban centre and non-remote, remote and isolated reserve). The community provided a positive point of access to health services and served as a source of information about various illnesses for some of the participants. At the same time, however, some communities did the exact opposite. The impact of TB information on TB knowledge within the community seemed to ultimately affect the participants’ feelings about receiving a TB diagnosis as they feared that others viewed TB as a “dirty disease” and only affected poor people. As a result, participants from all communities, to varying degrees, experienced shame and stigmatization. Additionally, participants described fears about returning home and not being accepted back into their communities. The findings are described in the following sub-themes: (a) accessing health services; (b) tuberculosis information within the community; (c) stigmatization, shame, and lack of confidentiality within the community; and (d) unhealthy communities. It is important to note that in each of the sub-themes, the TB experience varied for participants living in the different types communities.

Accessing Health Services

Throughout the interviews, it was evident that access to health services was not equal among all of the participants, and this sub-theme provides the largest point of contrast between the participants' description of their TB experience and community setting. When the urban and non-remote reserve participants finally sought a diagnosis, they accessed walk-in clinics and hospital emergency rooms. Participants from remote and isolated reserves, on the other hand, described going to their local nursing station or having a TB nurse visit them in their homes. The diversity of where a diagnosis was sought and/or received heavily influenced the TB experience; it either helped the participants get treatment as quickly as possible, or had them returning again and again because of misdiagnoses and deteriorating health.

The participants from urban centres and non-remote reserves described their experiences of seeking a diagnosis as being largely negative. They presented with symptoms commonly associated with TB: "night sweats," "chills," "coughing up phlegm," "a loss of energy," and "losing weight." Some even presented with more extreme symptoms such as "collapsing," "losing bowel control," and "feeling like [they were] gonna die." Many times they were told they likely had "pneumonia," "bronchitis," "a cold," or a "chest infection." Overall, participants explained that the doctors would listen to their chest, or order a chest X-ray, and then prescribe them with antibiotics, iron pills, Tylenol 3, anti-depressants, and/or puffers. One participant recounted a particularly emotional experience. She had gone to various walk-in clinics and had been prescribed antibiotics and puffers a number of times. Her illness had gotten so bad she could no longer control her bowel movements and "every time [she] moved something would come out." Her illness reached a point where:

> I was totally sick. Even before I came here like I have my washroom upstairs. One morning I couldn't even move. I was just stuck. I couldn't move my legs. My husband had to carry me upstairs to use the washroom. That's how bad the diarrhea got past my body. (Manitoba, Urban Centre)

It was after this that she went again to a local hospital and was told by a doctor that the aches she was feeling in her stomach were being caused by colitis. She was administered an invasive, painful, and ultimately unnecessary colonoscopy which had long-lasting repercussions. She stated, “they put something up my colon and I can still feel it. It’s like a rip or something. I don’t know what it is.”

A number of urban and non-remote reserve participants were also given unnecessary prescription pills during the process of seeking a diagnosis. One participant stated “I went to go see my walk-in clinic doctor...He gave me a box of cough syrup and some penicillin.” The interviewer asked if she had been administered a sputum sample to which she replied, “he just gave me a pregnancy test...And he thought I had bronchitis...He gave me some pink pills. He said, ‘these will last you.’ There’s 500 I think small pink pills. So I took those all week.” Another participant shared a similar story about being prescribed antibiotics:

> I’d go to the doctor but they just give me antibiotics it’d last for about a week. As long as I was on those medications I was okay. As soon as I stopped the medication I’d be sick again...They thought I was going through menopause so they tested me for that because I had a hysterectomy in 2006 I think it was. (Manitoba, Urban Centre)

The desire to gain a proper diagnosis and the fear of dying had patients returning to the same walk-in clinics and emergency rooms multiple times. One patient stated he saw approximately four different doctors at the same walk-in clinic before he got a proper diagnosis:

> I went to the Medi-Centre on Jasper...where I usually go and I saw, I don’t know how many different doctors there...and then my...sickness was progressing....I kept going and I even came to a point asking them if they can check my phlegm...I was terrified so the doctors kept telling me that nothing was wrong with me. I kept going and going. Finally this one doctor, right away, even before he examined me, he gave me paper towel to cover my mouth. Right away he knew. (Alberta, Urban Centre)

Another participant shared a similar experience of seeing multiple doctors in the hopes of receiving a diagnosis:

> I was trying to find out what was wrong with me and one doctor had tried to give me, what do they call that for depression? Antidepressants. They tried to put me on antidepressants and I'd say "I'm not depressed. I'm not, there's something wrong I'm not depressed," and so I refused to take the antidepressants and another doctor just kept giving me different pills, so finally I had about ten pills. (Saskatchewan, Non-Remote Reserve)

Often times it was the participant who had to continue to push for a proper diagnosis, or mention TB for doctors to administer the appropriate tests. One participant had been feeling sick for a while and her cousins had told her she was displaying the signs of TB. She decided to go to a nearby hospital because her reserve community did not have an X-ray machine:

> They gave me an X-ray and told me I had pneumonia in my left lung. They gave me enough antibiotics for two weeks and it seemed like it didn't work. So I went back to the same hospital and saw a different doctor but this time I told them I was in contact with someone that had TB. It was a lie but I wanted to be tested. (Alberta, Non-Remote Reserve)

One of the biggest frustrations noted by the urban and non-remote reserve participants was that they lacked a consistent family physician, in an environment where having a family physician is expected. As a result, they did not know where to go to get a proper diagnosis. One participant explained:

> The doctor told me I had to go see my family doctor. I didn't know who was my family doctor so I went and drop in on these walk-in doctors...I walked in and I say "I'm really sick, you know. I got sore ribs on both sides" and he gave me some painkillers. (Alberta, Non-Remote Reserve)

Another participant described a similar experience in attempting to seek help for his symptoms:

> He said, "you should go see your family doctor. This is for emergencies." I said, "doesn't this sound like an emergency? It took me three times to come in here and you guys couldn't prescribe anything right for me being better? There's something going on here. First you guys told me it was bronchitis, now it's pneumonia. There you go. Not only that. You're the third different doctor that I've seen in emergency so I got three different doctors that don't know what the fuck they're doing." And he said "yah, well don't come. Go see your doctor next time." So right when I left there I made an appointment to go see my doctor a week later. Same fucking thing when I went to see that other doctor. I said

> “Those people in emerg told me I should come see you” and he wasn’t really my family doctor but he was still a physician to see. (Alberta, Non-Remote Reserve)

In addition to misdiagnoses, the participants who accessed health services in urban centres believed that doctors viewed them as attempting to abuse prescription pills. One participant noted:

> I kept going to the doctor. I kept going to walk-in clinics because I was feeling so, like my back was killing me, like I just felt like I had the flu all the time, and then my doctor thought it was the flu, and then when I’d run out, of course I’d been taking Tylenol all the time and if I knew I was gonna run out by the weekend, I’d go to the walk-in clinic. And then they kinda looked at you kind of funny like, “oh you know, you’re coming here for Tylenol.” Well just give me regular Tylenol. I’m not asking for, I’m not popping pills but they do, some of them kinda look at you funny especially over there but I made sure that I had Tylenol all the time just to get rid of that pain, you know. (Saskatchewan, Urban Centre)

Another participant had a similar story, "they took me to the hospital and gave me antibiotics, Tylenol 3s, something to get me high...Since then I got, I started taking the pills, sober. I still feel the pain, I keep coughing.” Another man had experienced a very difficult time getting a proper diagnosis in the same hospital. He had been working in camps and had tried to hide his illness for as long as possible. When his mother finally persuaded him to seek help he was met with misdiagnoses and doctors who believed he was looking to get high:

> I went to see that physician that’s supposed to be my own doctor. “I wanna get better man. I’ve been going to the hospital and all they’ve been doing is giving me codeine. They gave me these five pills about two weeks ago. I don’t fucking feel nothing. I feel like shit. I’m sore, I’m sick.” So he gave me a paper for X-ray. He said, “here you go take another X-ray.” I just took an X-ray and they just fucking finished telling me I have a bad case of pneumonia. “Why should I have to take another one?” He said, “well take another one.” I said, “I wanna get better. I’m fucking sick of this. I feel like shit man, look at me. I don’t feel healthy.” Doctor looked at me and he’s like, “oh here have some more codeine.” You know the codeine helps me for the evenings. I don’t mind that. But I want some more antibiotics. Like give me some antibiotics. “No. You don’t need it. You’ve got enough antibiotics in your system you should be okay.” “Those five pills are not gonna fucking last two weeks. Like it’s not helping me. Come on. Fuck. Look at me.”

> You know like I really got angry at him and he stood there and he just looked at me and goes “Well what do you want me to do? Here. Have some more codeine” “This is getting me high. Look at me. My eyes, I look like a fucking person that did pills all their life. I don’t take pills to get high. I don’t wanna get high. Does it look like I wanna get high?” …I grabbed them and I walked out eh. He laughed, I said, “these are a fucking joke” and I just left him, I went home I took whatever codeine they gave me. (Alberta, Non-Remote Reserve)

In addition to being labeled as pill-seekers, the participants from urban centres and non-remote reserves believed that when they accessed health services they were met by doctors who were indifferent, “like they don’t care,” and had little time to spend on them:

> A lot of them just seem like they just don’t have the time. They just say, “Here you have bronchitis”...Like they don’t care. They just do a fast check, checkup and that’s it. They are just like “I think this is what you got” and just give you antibiotics...Pretty pissed off about that...Well somebody should have found out earlier instead of just pushing me aside like, didn’t even do the proper checkups. They just assume that I had bronchitis or it was the asthma...“It’s probably your smoking that’s doing it.” They never checked. (Manitoba, Non-Remote Reserve)

This left the participants feeling both angry and sad about their experiences in seeking a diagnosis. After dealing with accessing health services in an urban centre, one participant stated “[i]t made me feel sad nobody cared.” This was a point many participants made as they felt their concerns were not taken seriously. Another participant felt it took the loss of 50 pounds before doctors believed he was really sick:

> I didn’t know what it was, like I thought it was pneumonia the first time. First time I thought it was just a flu, and then it went on and on, and I thought maybe it was pneumonia and all that and I went to the hospital and nothing happened. Cause you go to the hospital. You go to Emergency and all they do is they just, it’s an emergency eh. Just tell the doctor there might be something wrong with you and they just kind of listen to your heart and all that...And every time I went to the hospital, same thing man. Finally after so many times, trips to the hospital I finally see a doctor who said “there’s something wrong with you.” I lost 50 pounds you know. (Alberta, Non-Remote Reserve)

This experience left many participants frustrated, believing that health professionals need to be more accountable. One of the participants spoke about the importance of doctors taking the concerns of their patients more seriously and for people to know that they should push for receiving a proper diagnosis:

> Somebody has to be reprimanded for misdiagnosing people. Maybe I'm the only one it's happened to. I'm saying it isn't, and it probably isn't. It's probably other people it's happened to, the same thing to me too, and it's unfortunate, you know somebody's gotta answer to it now, okay, 'cause you can't go around misdiagnosing people, you know, and thinking that they've just got a cold or, you know, he said to me "it could be a touch of pneumonia." I said "Okay that's fine." Then I went, you know, I just have to bundle up a little better when I work that's all. Take more cough medicines, that's all, and then it never, I never did get better. I just got worse. (Manitoba, Urban Centre)

Another participant, acknowledged that doctors may not be fully educated about TB and that there was still a need for further training. She believed this would help to ensure that others do not experience multiple misdiagnoses, as she had:

> Well the thing is, like even the doctors, they're not totally aware of TB themselves. Maybe I wouldn't have been sick so long if the doctors had checked out right from the beginning, when I said I had no energy. (Saskatchewan, Urban Centre)

While a large number of the stories shared by the urban and non-remote reserve participants about accessing adequate health services were negative, there were a few who spoke about the positive experience they had seeking a diagnosis in their city. In two urban centres in two separate provinces, there are health centres that serve large Aboriginal populations. One participant spoke of accessing a health centre he had frequented regularly, and after talking to a doctor, was immediately given a sputum test. This story was similar for a woman living in an urban centre who did not have a family doctor but would commonly access an inner-city health centre. Because she had built a relationship with the health professionals in the centre, they were able to see her health deteriorate and she received an accurate diagnosis.

In contrast to most of the urban and non-remote reserve participants, the participants from the remote and isolated reserves knew exactly where to go when they were ready to seek a diagnosis for their symptoms; they accessed their local nursing stations. While it was noted by one participant that "people in smaller communities have no access to doctors" and in order to see a doctor it was usually through a lengthy referral process, their local nursing station had TB nurses and community health nurses who were invaluable in providing necessary health services. The remote and isolated reserve participants reported that they had close relationships with the local nurses and were comfortable seeing them, which had a positive impact on many of the participants. One participant noted:

> This health nurse, well not a nurse but she works for the nursing station for a long time now, over 30 years now, 20 years. She always comes, every time she sees me then she will just, you know, talk to me even though when I feel sad and I'm just walking and then she'll just come out and say something...She started talking to me you know. And she always does. (Saskatchewan, Isolated Reserve)

Another participant described the friendship he had formed with the nurses in his community:

> We used to know the nursing station staff by name, like the nurses. They'd come over unannounced. They would just walk in and sit down, grab a cup of tea. To me it was okay. They were our friends. We would take 'em fishing in the summer time. (Manitoba, Isolated Reserve)

The access to, and relationships with, their local nurses and other employees in the community nursing station resulted in quick diagnoses. Participants explained that they were given Mantoux tests, sputum tests and chest X-rays after seeing a nurse. One participant noted that he had gone "to the nursing station and they just found out right away." A young girl had been experiencing pain in her chest, decided to go to the nursing station, and was given a chest X-ray. She explained, "right after I had my chest X-ray that's when the nurse, he was looking through the book, and he saw. He called [the TB nurse]. There's something. It looks interesting." She was then Medivaced out of her community to a nearby urban hospital to receive treatment. Oftentimes, participants noted that they were asked to provide a sputum sample, which would take a couple of days to come back. However, someone from the nursing station would follow-up with them when their results were in:

> The nurse came over to my house and they told me "how you feeling?" "Feeling sick." Well I went to the nursing station but you guys gave me this Tylenol this Motrin but it doesn't seem to help eh. I started feeling my chest is losing, I thought I was short of breath now eh. They said, "you have to come with us" you know. I said "okay" and I started walking outside and went to the truck like I was having a hard time breathing you know that stuff like talking to me and said, "how is your chest?" And I just told them how is it and they gave oxygen you know, breathing. That's when they just told me "you have to go" so at 7 o'clock at night they took me over here and I stayed downstairs for 15 minutes and they just flew me to Saskatoon. (Saskatchewan, Isolated Reserve)

For the isolated and remote reserve participants, there were far fewer examples of misdiagnoses and/or inappropriate prescriptions for antibiotics. In turn, because the nurses were embedded in the reserves, they knew of the illnesses that were prominent among the community members, and could easily identify TB symptoms and administer the correct tests.

Tuberculosis Information within the Community

In addition to access to health services, it is vital that communities have access to appropriate health information. Participants from the various community settings across the Prairie Provinces described different availability, and access to, TB information. It was noted by many of the participants who lived on-reserve that their community health centre or nursing station provided TB information to all community members. This information was disseminated through posters, pamphlets, and/or TV and radio broadcasts However, not every reserve was equal in how much TB information was provided; many of the non-remote reserve participants noted that they had never seen TB information available in their community health centre. Valuable annual check-ups were in place in a number of remote and isolated reserves, which participants attributed to catching their TB before it got really bad and saving their lives.

Community health centres and nursing stations served as a central point of information sharing, and through the use of frequent community health meetings, health professionals had the opportunity to get a large number of people together to talk about health concerns impacting their community. A number of participants noted seeing TB information such as, "a big chart [about TB]…everybody can read it," "[r]eading articles in the Health Centre," and "I seen posters, TB, showing lungs, stuff like that." One participant who had moved into an urban centre acknowledged that his home reserve had taken on the task of getting people together to have meetings:

> I don't think, well nowadays it's not hard to deal with it [TB] because there's help and back home they have a lot of support too, like they'll have meetings like once a month in the town hall and everybody will go there to pray. (Saskatchewan, Urban Centre)

Many of the participants from remote and isolated reserves spoke about their communities having TV and radio broadcasts that highlighted health topics and encouraged individuals to get checked out if they were presenting with any symptoms. One participant stated:

> The information is there. We put on a local TV show. Talks were given by public health nurses, and we put on local TV show. We tried it. Last year when people were coming down with TB, like quite a few weren't tested and we put on this DVD that runs for about half an hour or so and we tried to put it on once a day and I know the information is at the nursing station which hands out pamphlets and nurses used to have a once a week, they'd have a show on local TV where people call it. (Manitoba, Isolated Reserve)

He further noted that the Elders in his community would tell their TB stories and experiences to the younger generations. "[W]e wanna bring it up and have an open discussion on it, on anything as long as the community is aware of what we wanna do." Regular tests were often set up in an attempt to diagnose as many people as early as possible. It was because of this routine testing that one participant was diagnosed with TB prior to experiencing any symptoms:

> I didn't even have any symptoms at all, until the X-ray team came…I saw my aunty sitting there and they were still doing chest X-rays so I said to myself "should I go there get this done while I'm in here hey" otherwise I probably wouldn't have did it, you know. (Manitoba, Isolated Reserve)

One participant noted that regular check-ups would be of great benefit to her community as well. "There's one lady that wanted to have the whole reserve checked...It would be nice if everybody was checked...I wish somebody would talk to [the community] about that. The nurses should talk about that too."

Access to TB information did not necessarily mean that participants sought a diagnosis sooner. As one participant stated, "in the community it is not the lack of information" that causes TB to stick around. One participant noted that workshops were being offered in the community on various illnesses; however, attendance was low as the timing of the workshops made it difficult for people to attend:

> They do workshops on it, but like, very few people go because they either, some of them will have jobs and they can't go and some are elderly and can't walk or leave their house...They'd have, like people come in and they would have a one day workshops for one day in the gym. They'll send papers out and invite people to come. (Alberta, Non-Remote Reserve)

One participant living on a reserve where a TB nurse provided TB checkups explained that getting people together to talk about illnesses was hard. He stated, "[t]here's a nurse that goes around...They do mostly TB checkups...but to get people together to talk about it is pretty hard, especially my own town people, they're hard to get together." A number of participants admitted to seeing information about TB, however they still did not understand what it meant to have TB.

One of the participants had seen a TB poster in her community health centre but was still confused about the illness: "I wanted to understand what it was...Cause it just said TB and then I kinda read that really long word." This was expanded on by another participant who noted, "before I ended up in here I went to the meetings and they would talk about TB and my attitude was 'well I'll know when I get it.' I think that's how most of the people are at home." Some participants believed that TB is "generally accepted that it's there" that they were doing everything right in educating their people; "people already know all how it is transmitted from one person to another." Another participant admitted he had heard about other workshops taking place in his community but could not recall if they were about TB, and indicated that the workshops need to be better promoted:

> In all the years that I've been back, I've never sat and listened to information sessions on anything. Like where a qualified person comes in and says "here's what TB is all about and here's what HIV is and here's what" and if they did it, it was not very well advertised and I don't know. There's gotta be something done. It's gotta be implemented in the schools or compulsory some, something. There's gotta be more education. (Saskatchewan, Non-Remote Reserve)

In stark contrast to the non-remote, remote, and isolated reserve participants' experience, urban participants did not know where to look for TB information and did not remember seeing any prior to becoming infected. One participant emphasized the importance of having more education accessible in all health services facilities and not just in TB clinics:

> It wouldn't hurt to have like pamphlets lying around, not just in TB clinics...It should be around like in regular clinics and places like that, just so people can pick them up when they have nothing to read. Maybe there should be less magazines around in these kinds of places so while they're reading they'll reach for that instead of a Chatelaine or any other magazines. (Alberta, Urban Centre)

Many of the participants expressed the need for increased TB information for those affected with TB, as well as for the general public. One participant explained that because she was not able to identify the sickness in others, she became infected with TB:

> TB is not a very glorious disease. I had no idea how bad it was. Education doesn't educate those who were not sick how to look after people who are sick. People are not told in the [general population], they're not told, "well this is what we have to care for. This is what it means to be ill." You have to have some regard. You can't take for granted your behaviour with a person because they may be suffering, weak, strained. So education is not only improving the well-being of a person in bad health but it's, you know, pro-active, prior intervention for people who don't wanna get sick or for people who want to properly care for people who are sick. (Saskatchewan, Urban Centre)

The lack of available TB information was acknowledged by many of the participants as being linked to the lack of preventative measures being taken by communities, policy issues, and a gap between younger generations and their elders. "It's frustrating...Years ago TB clinics used to come onto the reserve. The whole reserve...not just one person...was vaccinated." One participant noted that because TB was not a widely visible disease, there were fewer discussions around the illness:

> So that disorientation and the disconnect with social agencies and the public over these matters makes you the expert because you're working with it every day of your life and no one else is talking about it, knows about it, shares information about it...[TB] is not a glorious disease. It's hidden… It's not an issue of the day. It's not the choice of the week. It's not the buzz word of the month… And this government prided itself on having cured the incurable…Just as the world claimed to have gotten over polio, they thought they had destroyed the white death but they were wrong and had to go from victory to failure in the process. Now, yes that's generation but in terms of party politics [TB] wasn't the popular issue to bring up… And so fundamentally the education is not there. They were wrong, whatever the decisions were made at the time were wrong and didn't work. A lot of lives, peoples lives were destroyed. (Saskatchewan, Urban Centre)

A participant, who had grown up on a northern Saskatchewan reserve where TB was more prevalent, explained that there was a common disinterest in the available TB information by the younger generations:

> The young people, they seem to brush it off...But the old people are, it's almost mythological, how deadly it is, you know. They always make it like a third person. The sickness. It'll come and get you or whatever. ...Because it's out lurking around there. I remember that, and it must have been more so amongst the old aunties, and even when I was a kid. (Alberta, Urban Centre)

As evidenced by the participants living in non-remote, remote, and isolated reserves, the community has the opportunity to provide its members with access to important health information. A lack of TB knowledge, whether it is through a genuine dearth of available information or due to a disinterest on the part of the people to learn about various diseases, was thought to greatly impact individuals' capacity to know what they were experiencing when their symptoms were presented. During the interviews, many of the participants expressed that they were surprised that TB was still a problem and that they did not know they could still become infected. Participants who lived in urban centres highlighted the need to have more information available to everyone so that more individuals in the general public can also appreciate presenting symptoms in others.

Stigmatization, Shame, and lack of Confidentiality within the Community

The lack of information about TB led participants to believe individuals in their community held negative views towards the illness. The participants expressed fear of being treated differently when they returned home from treatment. A number of participants acknowledged that other people hold negative and inaccurate perceptions about TB. As one participant noted, she felt "bad" and "ugly" and believed her friends would distance themselves from her after hearing she had TB, which made her "feel so low." When describing how they felt about seeing other community members when they returned home, many participants used words such as "embarrassed" and "ashamed." This was, as one participant noted, because TB was not perceived well in his community:

> I think most people are just embarrassed to admit that they had TB or they know somebody with TB. So people know it's there, information is there and everything but it's just that nobody talks about it and that basically everybody's shy or embarrassed to talk about it...Just people being stereotyped. (Alberta, Non-Remote Reserve)

This was more prominent among the participants who lived on a reserve, who acknowledged that many community members already knew about their diagnosis even before they returned home. Shame over their diagnosis, however, was a feeling expressed by many participants regardless of where they lived.

The participants described feelings of isolation and judgment for having TB, sometimes even before they had returned home from the hospital. Many expressed the fear of people not wanting to be near them and that they were being "looked at funny." One participant stated that she was "ashamed of talking about it" while another voiced that she "was still shy cause there's this stigmatism that comes with TB. It's like you're dirty or you live a filthy lifestyle." One of the participants stated, "for me the first time I was diagnosed even like...I was ashamed of talking about it...I didn't even wanna mention it." She further acknowledged that people in her community "don't wanna talk to you, they don't wanna hang around with you...They think they're gonna catch the germs." It was described by a number of participants that TB was considered a "dirty disease." Throughout their interviews many of the participants described how they felt "disappointed" over receiving their diagnosis. One participant even expressed that she was "hoping for something else" as:

> People in [my community], when they hear the word 'TB' they're all "oooo…Oh my God, or something like that"…Like they say "oooo, gross"…cause they are afraid of TB…They're scared they might catch it too I guess. (Manitoba, Isolated Reserve)

She went on to state that news about her TB diagnosis had "spread already" and because everyone already knew she was going to "hide her head…hide my face…not go out" when she returned home. Another participant noted a similar sense of shame over being diagnosed with TB because people from her home community viewed the illness as being dirty:

> When I was first diagnosed I was sort of expecting it but I never really, at the same time I never really thought about how it would affect me until I was actually diagnosed. I felt ashamed...I guess it's the way I was educated with it. I was never really educated how you can get it and I think it's the way people perceived it up North was that it was, you know, a dirty kind of disease, how you can catch it...From what I've heard most people catch it from places where, places like bars and stuff where really unhealthy people hang out. (Alberta, Urban Centre)

A number of participants were worried that people were going to think they were contagious and that everybody would "turn" from me. One participant believed that her friends and community members "won't welcome me into their homes any more cause they think I might be contagious. I might pass it on to them. That's how they think. I've heard about this." Another participant stated that she felt like "a loner" and that she believed people were going to "act different [and] say oh look she has TB." She explained that she was worried that "people will be scared to be around me" and stated that she had to "isolate myself when I get back." These feelings were echoed by two other participants who stated "I just feel like they're gonna blame me...like they're gonna say that I'm gonna pass it around" and "I hope nobody will want to be afraid of me." A participant from Saskatchewan who had returned home already from her treatment stated that people were saying, "don't go by her." It was because of these similar feelings of embarrassment that one man was afraid to cough in front of others "even when I wanna cough or sneeze I won't do it around people."

Participants expressed their sadness over being treated differently the moment they were diagnosed. When one participant was being flown out of his community for treatment, the pilot made him feel uncomfortable:

> Like when I came down here on a Medivac, the pilot told me to sit in the chair at the back…And he said “Now don’t touch anything.” He wouldn’t handle my bag. I tried to give him my travel warrant. He put it, he held out a paper bag to me and said “put it in there”…He was scared…That made me feel, I wasn’t too comfortable with that. Not because of what I have but because of his ignorance I would say. (Manitoba, Isolated Reserve)

Another Manitoba participant felt that “people are standing a certain distance from me” and that when she was brought in to treatment “I felt like I was paraded through the emergency room doors.”

There was a common thread of concern voiced by a number of participants who acknowledged that there was an issue around confidentiality and their diagnosis. One participant had been very involved with his community and had worked on maintaining the communication towers for the local TV and radio stations. He noted that when word spread about his diagnosis to community members, his coworkers refused to work with him and that “some people are scared.” He stated, “[o]ne pilot refused to fly me.” Another participant believed that because he had a certain last name, it was widely shared within his community that he had TB:

> Once I got diagnosed I started feeling better but I was still shy ‘cause there’s this stigmatism that comes with TB It’s like you’re, you’re dirty or you live a filthy lifestyle and you even get that in First Nations and it’s supposed to be confidential and there’s nothing confidential. Everybody knew I had TB. Everybody knew I was getting tested…It’s the people that are in, in what they believe to be, whether they’re better off or they’re in some kind of political better power, everything’s hush hush and I just recently found out that this one certain family is riddled with TB and nobody has heard a word about that whereas like say I’m just because of my last name I’m on a lower class scale and everybody had heard that and then there’s even poorer people than me and my family name and everybody hears all about them... There’s no such thing as confidentiality because they’re not professional enough to and then you reach a point where you just don’t care but yet you’re, you gotta overcome what they’re thinking that TB’s dirty. For people that live like pigs or something it’s like lice. They figure well you know, you know lice is not just a native problem anymore. It’s, but yet there’s a stigmatism. (Saskatchewan, Non-Remote Reserve)

A lack of privacy was a concern expressed among the participants mainly from reserve communities, which further compounded their fear of stigmatization. Participants spoke about certain families in the community being granted the privilege of privacy, while others did not receive the same consideration. Those who held political power such as a Chief and council members did not have their diagnoses shared with other community members. Finally, one of the participants believed that “the majority of people [know I have TB], small community, people talk.” She further expressed fear that if her family turned away from her as well, she “would have nowhere to go.” While this lack of confidentiality was most commonly expressed by the participants on-reserve, some of the participants from urban centres expressed similar frustrations with service providers. One participant stated, “you know, this is still a small town regardless of all the privacy and all of the professional crap everybody knows everybody’s business ‘cause they talk about it.”

Unhealthy Communities

This final sub-theme is a culmination of the stories shared by participants about how much an impact the community had on the TB experience. Many participants, regardless of where they lived, indicated that poverty, an unhealthy lifestyle, and a disregard for communal health compounded the TB problem. As the previous sub-themes have highlighted, the community plays an integral role in community members’ access to health services and general health information, and in providing a safe place for individuals to live with TB without fear of being treated differently. When these things were not provided it seemed that participants viewed their communities to be generally unhealthy, and that community members had little regard for spreading their illness to others. The participants who were homeless and living in urban centres in particular highlighted the concern they had over their living conditions and believed that their lifestyles and the people they were associating with led to their TB problems.

The community's own notion and culture of health significantly impacted the participants. A number of participants described the importance of having a healthy community for the mutual benefit of everyone. However, a number of participants stated that some community member's disregard for the health of others allowed the disease to be easily spread. Participants spoke at length about how illnesses were shared "[b]ecause nobody cares, that's why. They don't help each other." Tuberculosis was viewed by other individuals as "just another illness" and a number of participants stated that oftentimes community and even family members were not willing to get tested or disclose their diagnoses. A participant was asked to think of someone who he considered to be healthy, to which he stated, "I don't know nobody around here that's healthy." Findings presented in the previous chapter showed that participants felt fear and guilt over potentially spreading their illness to others. However, they commented that others did not appear to feel the same way:

> Now that I'm here it's opened my eyes eh of how many people like I've infected and I think that's the attitude that people have at home is that they don't care until they get it, you know, so they don't make an effort to go for a chest X-ray…Just the same people that always go….The teachers make sure that they go in and have a chest X-ray. Okay and as for the people that are just living at home, they don't even make an effort to go get a chest X-ray and I think that's how this TB is spread around. (Manitoba, Isolated Reserve)

The participants who lived in urban centres often described how living in poverty was breeding diseases and negatively impacting their overall health. Many participants were living "in poverty in the inner city with reality and death lurking at your door" and one participant described the individuals around him as a "sick puppy litter." Another participant described the communal conditions in which inner city people are often living, which exacerbated the problem:

> That’s the reality of it, you’re sharing cigarettes and you’re sharing beer and sharing joints and pipes and slobbering all over everything you can get your hands on and the aerosol in the air is wet with, you know, sprayed mucus and so survival, it’s maintenance, you know, is instinctive and it’s like the black death. It’s a turn off so stigmas and what that does socially and communally I’ve isolated myself completely for more than a year and, but people are, you know, in communities are marginalized like lepers. (Saskatchewan, Urban Centre)

When this is the reality the participants are living with, it was noted that there were few options for a better or healthier life. However, one participant spoke about the importance of being able to turn to spiritual elders in his community to bring him back to a healthy lifestyle:

> But what I found was I really circled around the spiritual elders to get me through the depression when I didn’t know what was wrong with me, and that helped. Like I was still depressed, I was still anxious, my nerves were gone and my outlook on life, like I couldn’t work even if I wanted to but I couldn’t tell people and I think they were thinking I was lazy and then I went out drinking and they said “Ah. There he’s going back to his own lifestyle” sort of thing and but just now lately the energy is coming back a bit. (Saskatchewan, Non-Remote Reserve)

Elders and access to traditional healers were noted by a few participants as important community resources that provided a great deal of support to them during their TB journey.

Discussion: The Impact of Community on the Tuberculosis Experience

The TB experiences shared by the participants in the context of their communities revealed the largest differences and brought to light many inequalities faced by Aboriginal peoples living in various community settings across the Prairie Provinces. In an effort to compare the sub-themes across communities, Table 4 identifies where similarities and differences occurred across the community settings. It was evident from the interviews that the participants did not have equal access to health services and TB information. When accessing health services in urban centres, the participants described very negative experiences. Urban and non-remote reserve participants shared their experiences of going to hospitals and walk-in clinics, seeing multiple health professionals (who they viewed as indifferent and discriminatory), being administered various medical exams, being given the wrong diagnosis, and ultimately being prescribed unnecessary medications. They lacked a health professional with whom they could form a relationship and with whom would ultimately provide them a level of continuity in their care. This was in complete contrast to the participants from the remote and isolated communities who knew where to go with their presenting symptoms (nursing stations), knew who to talk to (TB or community health nurse), and could be followed up with when tests results were not immediately given. Further to this, the participants sought a diagnosis from individuals who they had formed relationships with and who were embedded in their community. It became clear in these findings that a TB diagnosis is best supported if individuals have access

Table 4

Community Sub-theme Comparisons across Communities

Sub-theme	Urban Centre	Non-Remote Reserve	Remote Reserve	Isolated Reserve
Accessing Health Services	Participants accessed emergency rooms and walk-in clinics, were misdiagnosed and experienced discrimination. Participants did not have a consistent health professional to go to.		Participants accessed nursing stations with TB nurses, and received a proper diagnoses.	
Tuberculosis Information in the Community	Limited to no TB information available.	Varying degrees of TB information available at community health centres.	TB information available at nursing stations through TB posters, pamphlets, and charts. Community radio and television stations broadcast TB information.	
Stigmatization, Shame, and lack of Confidentiality within the Community	Experienced shame and some fear over returning home and concern over service providers sharing diagnosis.	Strong feelings of shame and fear over returning home and being stigmatized by community members, family, and friends. Confidentiality of diagnosis a large concern for participants.		
Unhealthy Communities	Participants expressed that community members are not proactive in seeking a diagnosis and paid little regard to spreading illnesses.			
	Participants raised concern over how poverty and surrounding themselves with sick people promoted the spread of disease.			

to a consistent health professional, receive continuity of care, and health professionals have an awareness of the illnesses that predominantly affect the population they serve.

These findings are supported by current literature which clearly highlights the inequities Aboriginal peoples face when accessing health services in Canada (Benoit, Carroll, & Chaudhry, 2003; Browne, 2005; Browne & Fiske, 2001). Tang and Browne (2008) found that Aboriginal peoples face discriminatory experiences while attempting to access health services. Their participants perceived they had been treated poorly because they were seen as “drunk Indians” and that because they were Aboriginal, health professionals brushed them aside. Further to this, Tang and Browne found that many Canadians and health professionals actually believed Aboriginal peoples were abusing the system to access drugs and that they overuse the emergency room for their primary health needs. Firestone et al. (2014) found that 10.6% of the adult urban Aboriginal population accessed an emergency room six or more times in the previous two years, compared to 1.6% of the adult non-Aboriginal population. The implications of not having a consistent doctor and using a hospital emergency room or a walk-in clinic as a primary source of health service provision resulted in the participants receiving multiple misdiagnoses, being given unnecessary medications, and experiencing extreme deteriorations of health caused by diagnosis delays. The delays in diagnoses left many participants feeling frustrated over the lack of competent health professionals who could properly diagnosis TB. The inability of the doctors in urban centres to recognize the symptoms as TB had negative impacts on the lives of the participants as their health extremely deteriorated.

When the urban participants had built relationships with and frequented health centres that worked primarily with Aboriginal peoples they did not receive multiple diagnoses and the health professionals took their deterioration of health seriously. This is supported by findings from Macdonald et al. (2010) who noted that the urban Aboriginal participants who accessed their local Native Friendship Centre had more positive experiences with accessing health services and viewed their relationships with health professionals as positive. By having care that supports Aboriginal peoples, they do not experience discrimination and they have a consistent source of care for their health needs.

Having a connection to a health professional who knows the individual and knows what illnesses are burdening their population proved to be very important in this study. The TB nurses were instrumental in providing quick and accurate testing for the participants from certain reserves. According to the community access forms for participants from the remote and isolated reserves in Saskatchewan and Manitoba, doctors made routine visits to the community, there were health representatives available, and they had access to an X-ray machine. The relationships the remote and isolated reserve participants had with their community health nurses were important in recognizing and addressing their deterioration of health. Many authors have described how important culturally safe environments are to improve health outcomes for Aboriginal peoples (Durey, Thompson, & Wood, 2011). This is further supported by the findings in a report conducted by The World Health Organization (WHO) (2006) which examined diagnosis and treatment delays in TB infected individuals at both the patient and system level. It was found that, in a study conducted in the Middle East, delays were often attributed to the health system. When individuals experience symptoms, they are encouraged to seek a diagnosis from their local health unit (Saskatchewan Ministry of Health, 2010). Clinics designated just for TB are available in each province; however, mainly just in the larger urban centres and they may be hidden in large tertiary hospitals. As many of the participants did not associate their symptoms with TB, they were heavily reliant on emergency room s and walk-in clinic doctors as well as on community health nurses to administer the appropriate test. However, in the current study, when general practitioners were the first point of contact for a diagnosis it was rare that a TB diagnosis was made. The implications for this are highlighted by the WHO report which indicates that health system diagnosis delays ranged from 5 to 90 days when a general practitioner was accessed, this allows the infection to spread further within communities and exacerbates the negative impacts TB has on the health of an individual.

Tuberculosis information proved to be an important piece of the TB experience for the participants. The findings from this study revealed that not all participants had equal access to TB information. Participants from urban centres described having the least available and/or accessible amount of information concerning TB. Unless the participants had prior knowledge about TB from their home reserves, they did not know what TB was and where to go to learn more. The availability of TB information on non-remote reserves varied between communities with some having pamphlets and posters and others having nothing. This was very different from the participants living in remote and isolated reserves where TB information was disseminated through television and radio broadcasts. Nursing stations also had TB information available through posters, pamphlets and charts. It was noted that routine TB tests are also available in these communities, which facilitated an early diagnosis. It is important to note that the availability of, and access to, TB information did not necessarily resonate with individuals as they still had difficulties recognizing their symptoms as TB, did not attend community workshops or pay attention to available TB information, and/or did not talk about the diseases impact in their community. Participants wished they knew more about the disease so that they could have noticed it sooner.

The importance of access to TB information on stopping the spread of TB has been widely studied (Demissie, Lindtjorn, & Berhane, 2002; Gele, Bjune, & Abebe, 2009; Melaku, Sharma, & Alemie, 2013). A majority of these studies were conducted in Africa, and found that the lack of TB knowledge coincided with the proximity to adequate services. Due to the remoteness of many African communities, medical information is often sparse, which impacts the knowledge citizens have about TB. The current study, however, has shown that proximity to health services was not a factor in access to TB information and the subsequent impact on participants' level of TB knowledge. All of the participants were in proximity to different types of health services (e.g., hospitals, nursing stations); while, the availability of TB information varied across the community settings the majority of participants remained confused about TB. Lienhardt (2001) found that the lack of TB awareness, knowledge, and information significantly impacts TB transmission rates. However, even when participants in the current study admitted to seeing TB information, they were not aware they had TB and did not acknowledge the severity of their symptoms. The most effective form of early TB diagnosis, in this study, proved to be through the use of routine TB testing set up in the communities. The use of proactive health campaigns in the fight against TB is supported by Alvarez et al. (2014) who used a TB health campaign to encourage individuals living in Nunavut to get tested for TB.

The importance of access to TB information is also critical in the fight against stigmatization, which was widely spoken about by the participants regardless of where they lived. Previous studies have shown that poor knowledge about TB impacted the patient's attitude about the disease and that stigma is a social determinant of health which impacts health seeking behaviour (Abebe et al., 2010; Courtwright & Norris Turner, 2010; Jaramillo, 1999; Tolossa, Medhin, & Legesse, 2014). Tuberculosis has been viewed as a dirty disease, only affecting the poor and lower class, and for those who do not take care of themselves (Courtwright & Norris Turner, 2010; Juniarti & Evans, 2011; McEwen, 2005) The stigma felt in this study by participants further led to feelings of shame and guilt, which caused them to want to isolate themselves from others. Many participants went so far as stating that they feared holding their children, sharing utensils with family members, and coughing in front of others even after they had begun treatment. These feelings expressed by the participants in this study are echoed in other studies, which found that participants believed community members might isolate a TB patient and be fearful to share utensils or eat their food in case they could also catch TB (Atre, Kudale, Morankar, Gosoniu, & Weiss, 2009). Many would admit to trying to hide their disease to protect themselves from adverse community reactions and a loss of social status. Participants in the current study did note mixed feelings about receiving their diagnosis; while some revealed they were relieved that it was not cancer, others stated they were saddened to find out it was TB. Studies have looked at the most effective means of reducing stigma and have found that programs should target the individual and their ability to face stigma, which subsequently targets community norms (Hadley & Maher, 2000; Heijnders & Van Der Meij, 2006; Macq, Torfoss, & Gethun, 2007). Tuberculosis clubs were identified as being highly effective at decreasing social isolation, facilitating inclusion, and/or increasing the ability to be visible and accepted (Demissie et al., 2002). This is an important consideration for future TB policies and practice as those going through TB treatment could be brought together and/or utilized to share correct information about the disease and thus reduce stigma.

This study brings to light a number of important areas that are disconcerting for Aboriginal peoples living in different community settings, health professionals, and the general public. All of the participants faced their own unique and equally difficult barriers from seeking a diagnosis to being treated for TB. The participants who sought a diagnosis in an urban centre shared how difficult it is to gain a proper diagnosis when there is a lack of relationship between health professionals and patients. They feel discriminated against by health professionals who may also not be fully educated around the illnesses that are affecting Aboriginal peoples, which can cause them to miss opportunities to correctly diagnose. Participants from remote and isolated reserves who accessed their local nursing station shared that the relationship community health nurses had with community members was seen as a positive influence on their TB experience, and was important in leading to a quicker TB diagnosis. This study also brought to light important areas of future consideration in regards to how TB information is developed and presented. Stigma can continue to exist when those who suffer from TB and their communities are not equipped with accurate information. Information and awareness for individuals and family members that are impacted by TB could empower them to request proper testing and to begin to dispel the inaccurate information proliferated in their communities. Therefore, a new approach needs to be taken so that TB is taken seriously but is no longer seen as a disease that affects dirty and poor people only. This will help strengthen the health of individuals, families, and communities.

CHAPTER 8: "I FELT ALONE": ISOLATION POLICIES AND THE TUBERCULOSIS EXPERIENCE

The previous three chapters have followed participants' TB experiences from the early stages of becoming sick, experiencing extreme symptoms, receiving support to identify their illness, and seeking a diagnosis. This chapter focuses on the final stage of the TB experience and illustrates how policies on isolation impact participants' well-being during TB treatment. The interviews were conducted with the participants while they were in the initial weeks of receiving treatment for TB. Treatment is handled differently across the Prairie Provinces with respect to isolating infected patients. In Alberta and Manitoba, highly infectious individuals are isolated in hospital; thus, Alberta and Manitoba participants were in the hospital for their interviews. In Saskatchewan, highly infectious individuals may be isolated temporarily in the hospital but are primarily allowed to return home to complete the isolation phase in their communities. Consequently, Saskatchewan participants were interviewed in various locations throughout their communities (e.g., home, community health centre).

The treatment for TB can be a frightening prospect, especially when patients are highly infectious (sputum positive), as the participants in this study were. They may face weeks of isolation and are required to take medication that can cause many side effects that leave them feeling nauseous, dizzy, and tired. As a result of being isolated for varying periods of time, the participants from all community settings shared feelings of being "sad," "really, really bored," "alone," "trapped," "lonely," "frustrated," "like they were in jail," and "isolated."

Essentially, participants' experiences across community settings and provinces can be described through two sub-themes (a) confinement; and (b) family and social disconnect. In the sub-theme, family and social disconnect*,* the TB experience differed slightly for the remote and isolated reserve participants who had to be flown out of their home communities to receive treatment, as well as for the urban participants who lacked social connections. Because of the heightened feelings associated with being flown out of communities and/or being isolated in hospital, the isolation experience draws primarily on participants' interviews from Alberta and Manitoba.

Confinement

The participants in this study were annoyed over not being "allowed to go anywhere else" or to "walk around" and they indicated that it was hard being "in bed and inside the room." Participants were used to leading independent lives and expressed frustration over being "trapped" in the same room all day. One participant noted "it was stressful for me. I have a history of anxiety and it was difficult to be isolated, with the door shut all the time." There was often little to do and the participants described feelings of restlessness as they could only occupy their time by watching television. A participant explained that it "[wouldn't] be so bad if you could go outside." This desire to go outside was shared by many participants, one in particular who stated, "I'm more of an outdoors person and they're keeping me indoors. It's so boring…I'm not allowed to go outside...Just lay on the bed and watch t.v. ...I miss home a lot. It's boring here." With little to do, participants were just getting through their day and trying to get better. When a Saskatchewan participant, who was interviewed at home, was asked how he felt about being in the hospital for the beginning of his isolation treatment, he stated, "[i]t was pretty hard I guess cause you just stay there and watch T.V. and just thinking too much. All you have to do is just get another pill or to just fall asleep." Another Saskatchewan participant was also isolated in a hospital for a brief period of time before being sent home. She stated:

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

Many participants compared their time in the hospital to being in jail and made comments like, "I'm sick and tired of it…It's, well, just to be in jail. I'm not allowed to go anywhere else." A grandmother felt like she was being arrested upon diagnosis and the experience of imprisonment continued throughout her treatment:

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

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

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

Another participant had warned his doctor, "[I] told my doctor 'I wanna get out of here. Give me a chance to see a way out. I'll sneak out of here.'" These feelings of isolation and being trapped were common among many participants and inevitably led some to actually run away. One participant stated, "[s]ometimes I feel like going home 'cause I never been out and never been this long outside of my house, my home. Just feel like going home sometimes." She later did just that:

> I'd rather stay out of the hospital...When I was there I snuck out even they said, "don't go out". They had to look for me. He didn't find me till two days after, when I went back…I went home, got tired of this place." (Manitoba, Urban Centre)

She was not the only one; another participant was sick of being stuck in a room all day and therefore decided to run away:

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

One woman from Saskatchewan had been transported to a small urban centre to receive treatment and said, “I didn’t feel like staying in the hospital. I was mad…I was supposed to stay there a month but I walked out.” Her doctors decided that she would continue her isolation treatment at home and was not brought back to the hospital.

Family and Social Disconnect

When the participants went into isolation, they experienced a great deal of sadness and feelings of disconnect over being separated from their family members. They acknowledged that their friends and family were often fearful of visiting because of the isolation setting. One participant described how her sister, the only family member in her life, drove her to the hospital but had not been back since the participant was diagnosed with TB, as she was “too scared.” Being in isolation caused many participants to feel as though people no longer wanted to be around them. Another participant stated, “[i]t’s like nobody don’t want you no more. You got a sickness and you can stay there until that sickness goes away. If it doesn’t go away you’re by yourself there.”

Participants who were parents noted that it was especially hard being away from their children. Children, who were often being preemptively treated for TB infections, lived far away, and/or were too young to come visit their parent in isolation. A mother expressed guilt over leaving her husband behind; she knew that he did not like her being in the hospital, because “he feels lost without me.” Another participant had also left her husband behind to take care of their eight children:

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

Participants often had to rely on family members to look after their children when they were removed from their communities. A young mother who had been transported from her community in southern Alberta to a large urban centre four hours north for treatment expressed guilt over relying on her parents to take care of her children and the possibility that she passed her TB to them:

> They’ve already done so much in taking care of the kids. Taking time out of their lives to watch my kids...[I] did not know what to expect I just felt guilt I was gonna be away from my kids for that long...I’m just worried about my kids getting sick too. (Alberta, Non-Remote Reserve)

Because the minimum age to visit patients in isolation is 12, she stated that her youngest child had called to yell at her to “come home now.” She explained that it was hard to hear her children having a difficult time without her, that she wanted to go home, and that “sometimes I’d be here crying.” In spite of receiving strength from family to get better, the separation from families often hindered the participants’ ability to remain positive and was noted to negatively affect them during their stay in isolation. Family members also experienced the emotional toll of separation. A grandmother stated that her children and grandchildren were “scared” about hearing she had to go into treatment, “they didn’t want to lose me.”

The feelings of disconnect were exacerbated for participants from remote and isolated reserves as they had to be flown out of their communities and away from their families for treatment. After receiving a TB diagnosis, a young participant stated that she was “disappointed. I felt alone in my room…I knew I was gonna get Medivaced out.” Another Manitoba participant expressed sadness about receiving her diagnosis because she did not want to go to the hospital, and she stated, “I don’t like staying here.” One participant found it very difficult to explain to her kids why they were unable to come visit as they would require a flight down to see her. Another mother had to leave her newborn baby behind when she was removed from her reserve to receive treatment. As a result she was unable to breast feed for the duration of her stay in isolation. One participant had to explain to his children that he would be leaving for a while which was hard on everyone:

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

The participants from urban centres without strong social connections also had unique isolation experiences. While those from remote and isolated reserves were distraught about not seeing family members, the urban participants without strong social connections had intensified isolation experiences because even if friends or family could visit, no one did. Those who noted their social connections were with individuals who lived in boarding houses, on the street, and/or in shelters explained that they had very few or no visitors at all during their time in treatment. One participant said she was “lonely” because she “had hardly any visitors.” The lack of visitors for some of the urban participants was often attributed to their friends not knowing where they were or their inability to get in contact with them. When asked about being in the hospital and if friends had come to visit, one participant stated, “they don’t know about me being sick. I’ve never seen them yet. I never seen those guys since I come in.” One participant was transferred from a small urban centre to a larger one for treatment. He stated, “[t]he only thing is, I can’t talk to nobody because I don’t know nobody around here. I hardly talk to people around here...I don’t know their numbers.” Another participant had not been able to speak to anyone since entering the hospital, “I haven’t been able to use the phone yet...They don’t really know what’s [happening]...I haven’t been able to get a hold of anyone so I don’t know what’s happening.” In acknowledging how difficult it was on people who did not have visitors, one participant stated, “[i]t’s harder. Some of them they give up right away. They don’t even, like they’re deserted like so they just give up and die.”

Discussion: The Impact of Isolation on the Tuberculosis Experience

The participants in this study, regardless of community setting, described a wide range of negative experiences and emotions while being isolated in the hospital receiving treatment for TB. Participants isolated in hospitals at the time of the interview were still very sick, were unsure when they would be going home, and were consistently disappointed and often angry that they were not allowed to leave. The impact that isolation had on these participants cannot be understated, as they felt as though they were in jail, being treated like prisoners. They experienced feelings of sadness over leaving their children behind, seeing them infrequently, and/or not being able to see them at all. The participants from the remote and isolated reserves especially experienced great anxiety and sadness over having to be Medivaced out of their communities. Another notable difference between community settings was for the urban participants who lacked social connections and were often left to go through treatment alone.

Studies have found that patients who are isolated for extended periods of time experience greater levels of anxiety, depression, anger, and feelings of imprisonment (Catalano et al., 2003; Gammon, 1998; Kirkland & Weinstein, 1999; Lewis, Gammon, Hosein, 1999; Tarzi, Kennedy, Stone, & Evans, 2001). The isolation of TB patients has long been documented as being difficult for both patients and families (Wassenberg, Severs, & Bonten, 2010). Most of the studies being conducted on the impact of isolation are with European participants suffering from various communicable diseases. There is a significant absence of studies on how isolation impacts Aboriginal peoples. However, what is known is that Aboriginal peoples value their kinship networks (e.g., Hansel et al., 2004), are highly mobile and move between communities and provinces, and enjoy the outdoors and living on the land (Long & Memmott, 2007; Notzke, 1994). Because of this and the historical negative treatment of TB among Aboriginal peoples (Drees, 2010; Kelm, 2005; Moffat et al., 2013; Shedden, 2011), it is understandable that isolation made participants feel like prisoners, forced to remain in hospital. And if participants fled, they increased the chances that their illness would spread to others.

Going through treatment alone or with limited access to friends and family can cause a number of negative effects on patients. Parents, children, husbands, and wives were separated for extended periods of time further impacting their relationships. The participants who had children expressed guilt over placing extra burdens on family members who had to care for their children. Participants in other research have echoed these feelings of guilt (Hansel et al., 2004). No current studies were found that have examined the experience of being separated from the family during TB treatment among Aboriginal peoples. However, research has shown that Aboriginal women living in remote and isolated communities who were removed from their home community to give birth experienced many disruptions and losses (Chamberlain & Barclay, 2000; Douglas, 2006; Kornelsen & Grzybowski, 2004). The mothers were no longer able to care for their family at home and felt extreme sadness and grief over their separation. Chamberlain and Barclay determined that the greatest mental and emotional impacts that out-of-community births had on Inuit women were the separation from their family, community, and culture. Furthermore, like the findings in this study, these Inuit women worried about the well-being of the children they left behind.

The isolation policies that require individuals to remain in hospital or isolated in their community has a direct influence on the lives of individuals with TB and influences their social relationships and family dynamics. In order to make isolation more bearable for patients, health services may need to explore more holistic approaches to treatment that allow the family to be more involved or provide the patient with a more positive and stimulating experience. There is a large gap in the research on the emotional impacts that isolation has on those who need to be flown out of their home community and on those who lack social connections. The Saskatchewan participants typically only described negative feelings about isolation during their hospital stay, but not once they returned home. The practice of hospital isolation in comparison to home isolation should also be examined in terms of how it impacts the patient and their family while also considering the influence on TB rates. It was evident from this study that isolation in a hospital setting and a lack of connections with other individuals led to very negative feelings for the participants. Health professionals and policymakers have the potential to provide individuals from all types of community settings receiving TB treatment with a more positive experience which may influence the ongoing negative legacy of TB sanatoriums and treatment.

CHAPTER 9: CONCLUSIONS

Aboriginal peoples in Canada continue to be disproportionately affected by TB, with those residing in the Prairie Provinces carrying some of the largest burden (Long et al., 2013; Statistics Canada, 1992; Waldram et al., 2006). Despite new and targeted policies (e.g., *Health Canada's Strategy Against Tuberculosis for First Nations On-Reserve,* 2012) and advancements in treatment (Zumla, Nahid, & Cole, 2013), the TB rates across all three Prairie Provinces over the past decade have shown little improvement, and in some years, have actually increased. In light of these trends, there is an urgent need to understand the conditions that allow this disease to continue to spread amongst Aboriginal peoples. The purpose of this study was to understand the TB experience (from symptom presentation, to diagnosis, to treatment) among Aboriginal peoples living in different community settings across the Prairie Provinces. Aboriginal peoples are not a homogeneous group, and the disparities they face in terms of health and socioeconomic status vary by individual, group, and community history (Voyageur & Calliou, 2000/2001). An examination of available literature on Aboriginal peoples health disparities generally, and experiences with TB specifically, reveal that there are significant barriers (e.g., lack of culturally competent care, access to health services) that are impacting the health outcomes of Aboriginal peoples (e.g. Adelson, 2005; Brassard et al., 2008; Browne, 2005; Loppie Reading & Wien, 2009; Macdonald et al., 2010; Moffat et al., 2013; Public Health Agency of Canada, 2013). In an effort to understand the TB experience, this study drew on interview data from a larger research project, *The Determinants of Tuberculosis Transmission among the Canadian-born Population of the Prairie Provinces*.

The interview data were from 48 Aboriginal participants who lived in various community settings (e.g., urban centres, and non-remote, remote and isolated reserves) in the Prairie

Provinces. The interviews were conducted with participants as they were receiving TB treatment; however, the interview questions and responses were reflective of their entire TB experience. While there were tremendous similarities across all of the participants' TB experience, specific differences were also found and was attributed to the participants' community setting. These similarities and differences are important for understanding current supports that are in place and how they contribute to a positive TB experience, as well as the areas where improvements can and need to be made.

Illness is not experienced alone. Families, friends, and entire communities feel and carry the weight when someone becomes ill. In order to understand how an illness is experienced, the entire journey must be appreciated, acknowledging that the people, their relations, and other individuals they meet along the way influence their health. An ever present theme ran through every chapter and was noted to be the most important part of supporting the TB experience regardless of community setting. This common thread was the need for connection. Connections were integral in supporting the participants as they navigated their TB experience this meant having someone who can recognize a deterioration of health and being there during treatment. The implications of the need for connections on TB policy and practice are described in further detail below.

Connections

The participants, regardless of where they lived, blamed and placed the locus of control of becoming ill on themselves. Aboriginal peoples internalize and have a sense of apathy towards illnesses; this negatively impacts their self-esteem, mental well-being, and physical health (Chavez et al., 2008; Gruen & Yee, 2005; Heil & MacDonald, 2008; McMullin et al., 2012; Stanner, 1963). The residual effects of colonization particularly in relation to its disintegration of self-esteem and self-respect continue to permeate the lives of Aboriginal peoples and follow them as they move between cities, reserves, and provinces (Health Canada, 2012). Participants in this study reported that illness had become so deeply entrenched in their lives that it was normalized, none of the symptoms raised alarms, and they often came from unhealthy communities that promoted the spread of illness. The internalization and normalization of illness led them to live with TB longer, possibly spreading it to more people, and experiencing significant deterioration in their health. To fight against the effects of apathy and a normalization of illness and to get the participants to the hospital, connections were critical. Participants who had connections, regardless of who it was with, were encouraged to seek treatment. When family or traditional supports were not available, the participants in this study relied on service providers and other individuals they met on the street to help where they could. Social connections that are formed with service providers have been noted to positively influence personal health (Macdonald et al., 2010). When individuals lack connections all together they run the risk of going longer without seeking a diagnosis (Maulik et al., 2009). This was experienced by some of the participants in this study who ended up going to the hospital in an ambulance after their health had extremely deteriorated.

When the participants sought a diagnosis, the stories ranged from being met with discriminatory health professionals and receiving misdiagnoses (urban and non-remote reserve participants) to receiving an immediate TB diagnosis (remote and isolated reserve participants). The participants from urban centres and non-remote reserves lacked connections to a consistent health professional, their experiences were marred with negative encounters with health services, and they did not know where to go to receive a proper diagnosis. Consequently they accessed emergency rooms and walk-in clinics for their presenting symptoms. These findings are supported by previous research that highlights the inequalities Aboriginal peoples face when accessing health services (Adelson, 2005; Browne, 2005; Place, 2012; Sookraj et al., 2012; Tang & Browne, 2008). In contrast, the participants from the remote and isolated reserves had a connection to their nursing station and the nursing staff that worked within their communities. These connections proved to be invaluable as the nursing staff knew the participants, knew the community, and as such, knew the illnesses that were affecting community members. Consequently this improved the TB experience for the participants. Nursing staff who are embedded within a community are more aware of the illnesses affecting their community members (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002), have built relationships with community members, and have cultural and community awareness (Durey et al., 2011). All of these characteristics put community nurses in an advantageous position to identify deterioration in health sooner (Luker, Austin, Caress, & Hallett, 2000). The two urban participants who frequented health centres that serve large Aboriginal populations supports previous findings that urban Aboriginal community resources have the potential to improve the experience of accessing health services and health outcomes for Aboriginal participants (Macdonald et al., 2010).

When the participants inevitably received their diagnosis, the connections they had to a support system proved invaluable as they got them through treatment. Family involvement is critical during a patient’s health care journey (Botelho et al., 1996). Regardless of where the participants came from, they valued visits from their family members and spending time with them when they were in treatment. Being in isolation is an emotional and difficult process and has been found to increase levels of depression, anxiety, and anger (Catalano et al., 2003; Gammon, 1998; Kirkland & Weinstein, 1999; Lewis et al., 1999; Tarzi et al., 2001; Wassenberg et al., 2010). The emotional and mental toll of being kept in isolation in the hospital for indefinite periods of time weighed heavily on the participants. This appeared especially true for the participants who came from remote and isolated reserves and who were flown great distances to receive treatment, and for the urban participants, who did not have visitors throughout the time they received treatment. Connections to family and friends proved to be a positive mitigating factor that kept participants optimistic throughout treatment and motivated them to stay in the hospital. This finding aligns with those from previous research showing that, when family is not involved, participants are not as motivated to stay in and/or complete treatment when they leave the hospital (Gebremariam, Bjune, & Frich, 2011). Further to this, when patients are separated over great distances from their family during treatment, it proves to be very difficult on the patient and their loved ones (Chamberlain & Barclay, 2000; Douglas, 2006; Kornelsen & Grzybowski, 2004; Wassenberg et al., 2010).

Policy and Practice Implications

Connections played a central role in supporting the TB experience; connections to family, friends, health and community service providers, and to a healthy community. The importance of connections revealed the largest gaps in current policy and practice and brought to light critical areas where improvements need to be made. Recognizing the value of connections in policy development and practice needs to be addressed within the context of two specific avenues (a) improving tuberculosis information and knowledge; and (b) improving the inclusion of family and support networks for those experiencing tuberculosis.

Improving Tuberculosis Information and Knowledge

The lack of TB information and education was apparent throughout the findings and ultimately affected the participants, their family, the health professionals, community members, as well as the general public across every community setting. Being connected to nurses who had an awareness of the health concerns affecting their community improved the TB experience for the participants in remote and isolated reserves. This provides an important area of development for health professionals who work within urban centres. Although current policies acknowledge the need to test high-risk populations (e.g., homeless individuals, Aboriginal peoples from high incidence communities) and individuals who present with a cough that persists more than three weeks, there appears to be a lapse in the implementation of this policy. Increasing educational opportunities, resources about TB, and how it impacts Aboriginal peoples, alongside providing culturally competent training for all health professionals may help to reduce barriers and improve the experiences of Aboriginal peoples when accessing health services.

The need to improve TB information that is accessible and that resonates with all individuals was apparent from the stories shared by the participants. In spite of participants from some of the non-remote, remote, and isolated reserves acknowledging the availability of TB information in their community health centre and nursing station, they continued to be confused about the illness, how they got it, and how it could be spread. At the same time, participants from urban centres had no access to TB information and could not remember ever hearing anything about the illness unless they came from a reserve. The urban Aboriginal participants acknowledged the importance of forming relationships with service providers and others who helped them to get treatment sooner. Individuals who work with at-risk populations need to be better informed about the symptoms associated with particular diseases so they can provide the social support needed to encourage those at risk to seek appropriate services.

It is important that policymakers and service providers improve how information is currently being communicated to patients, their families, service providers, and the broader community, about TB. This could ultimately help to improve the capacity individuals have to self-diagnose and to help friends and family recognize the symptoms in others. Further to this, improving TB information and knowledge would help to reduce the stigma and shame experienced around TB (Abebe et al., 2010; Courtwright & Norris Turner, 2010; Gebremariam et al., 2011; Hadley & Maher, 2000; Heijnders & Van Der Meij, 2006; Macq et al., 2007).

Improving the Inclusion of Family and Support Networks for those Experiencing Tuberculosis

It is clear from these findings that being diagnosed with a communicable disease such as TB has serious and far reaching impacts. The involvement of family and other support networks appears to be vital to providing a well-rounded treatment plan. It is well understood that Aboriginal peoples live in collective societies, value their relationships with family and friends (especially during times of illness) (e.g., Hansel et al., 2004), and have strong attachment to the land and outdoors (Long & Memmott, 2007; Notzke, 1994). Therefore, leaving the family out of the treatment plan, removing individuals from their communities, and keeping individuals isolated for extended periods of time may not be the most appropriate form of treatment.

Saskatchewan's treatment policy allows participants to be isolated at home. While young children, babies, and individuals with weak immune systems may be required to leave the home during isolation treatment, visitors are allowed and patients can go outdoors. In turn, the Saskatchewan participants did not express the same struggles of comparing their time in treatment to jail. However, the TB rates in Saskatchewan remain relatively high in comparison to the Canadian average. At the same time, Manitoba requires isolation to occur in a hospital setting and has an even higher TB rate than in Saskatchewan, complicating what should be considered the best isolation practice. Alberta appears to be making the largest strides in their fight against TB. However, the Alberta participants also described very negative feelings while in hospital and likening it to jail. When they return home, the stories they share with their family, friends, and community may be very negative which could impact other people's desire to get tested.

It is evident that the isolation policies need to be improved so that patients, regardless of the community they come from, have family members or close friends included. Providing accommodation for patients and family has proven to be important for improving the hospital experience for parents of in-patient children (Franck, Ferguson, Fryda, & Rubin, 2015). However, the same can potentially be argued for all individuals who require lengthy hospitalization outside of their community. If individuals who are going to be isolated for lengthy periods of time can have family join them, this may ultimately improve the TB experience and decrease the negative perception Aboriginal peoples currently have towards TB treatment. The long-term influences of a positive hospital experience cannot be understated as the negative legacy of TB sanatorium treatment lives on (Moffatt et al., 2013). Aboriginal peoples continue to share the experiences of family members who long ago went to a sanatorium and never returned. This causes fear and anxiety over receiving a TB diagnosis. If individuals begin to access health services that provide them with a more positive experience and where family members and loved ones are more involved in the process of healing this could reduce the stigma and negative attitudes Aboriginal peoples have towards TB treatment. While the cost of providing support for more inclusive treatment may be more expensive at the outset, there is potential it could reduce costs in the long run as individuals may be more willing to go into the hospital sooner (prior to the infection getting really bad), their stay may be shorter, and they do not spread it to as many people. Further to this, by including more individuals in the TB treatment process, when patients return home they will have more support to continue their medication which would help to diminish the need for stronger TB medication due to treatment non-adherence.

At minimum, TB policy and practice needs to be improved so that patients in isolation in a hospital setting can engage in more activities and be allowed to go outside. In addition, more needs to be done to support those who do not have “typical” family and social connections. Individuals who lacked connections were left to get through treatment alone. Improving current practice within hospital settings and making environments more stimulating for patients could ultimately improve the socio-emotional experience for individuals who lack visitors and who can then possibly build relationships with others in the hospital. Currently, many hospitals provide children and youth with various activities (art and pet therapy) to combat feelings of boredom and depression over being in the hospital (Kaminski, Pellino, & Wish, 2002). It has been noted that TB clubs improve the socio-emotional well-being of individuals and decrease the feelings of stigma and shame (Demissie et al., 2003). Programs such as these could help to improve the hospital experience for patients. Further to this, TB clubs could be an important tool used in the community setting when the patients return home and have continued support from individuals who are going through/have gone through similar experiences. Additionally, individuals who lack social connections and are discharged from the hospital would benefit from being linked with community resources and supports. This would have the potential to remove the barriers of social isolation, provide a level of stability, which is helpful in promoting treatment adherence, and stop the spread and development of TB.

It should be noted that the most effective form of TB intervention was through the use of community wide TB testing. Participants acknowledged that if they had not gone on the day their community was offering TB testing they would have never known they had the illness. Being proactive and providing opportunities that motivate individuals to get tested because it is convenient has been acknowledged by other studies as an effective form of fighting TB (Alvarez et al., 2014). This could potentially be useful in inner city health or community centres that socially isolated individuals may frequent.

Transferability

The TB experiences shared by the participants provide important insights into overall experiences for Aboriginal peoples accessing health services. Improving tuberculosis information and knowledge and improving the inclusion of family and support networks for those experiencing tuberculosis can be extended beyond the scope of TB. While there are limitations to the extent findings can be universally transferable, one of the goals of research is to produce findings that can be shared outside of the original study setting (Malterud, 2001). The experiences shared by the participants can be, to a certain degree, transferable outside the scope of this research because they from a range of community settings and were of various Aboriginal backgrounds (e.g., Cree, Dené). There is an overarching need to improve the experience of Aboriginal peoples as they attempt to access health services and to improve the cultural competency of all health professionals. Further to this, the value of connections and the inclusion of family and support networks while experiencing illness does not need to be limited to only those experiencing TB. This is important to consider for Aboriginal peoples navigating health services in general.

Limitations and Future Research

The findings from this study highlight the critical need for improvements in TB information and knowledge and how TB policies need to be more inclusive of supportive networks. However, application of these findings needs to be done with a consideration and awareness of the limitations of this study. First, the sample of the remote and isolated participants was much smaller than the urban and non-remote reserve participants. Future qualitative research would benefit from a larger group of participants from these community settings to provide a deeper understanding of their experience with TB. Alberta has a handful of reserves that are remote but none of the participants in this study were from these communities. Including participants from remote reserves in Alberta in future studies, will provide another point of comparison of experiences between the Prairie Provinces.

The current study is a secondary analysis of qualitative data from a larger research project that sought to understand the determinants of TB transmission. Because this was a secondary analysis, there was no control over the questions asked, who the interviewers were, and the context in which the interviews happened. In addition, three different interviewers in the three different provinces conducted the interviews, and each interviewer focused on very different aspects of the interview guide. Therefore, certain themes were more prevalent in some interviews than others. For this reason, the TB experiences may not have been fully explored within every interview. Further to this, policy implications on the TB experience were not a focus of the larger *DTT Project* and, as such, were not typically discussed by the participants. This would be an area of potential future research as questions directly related to the TB experience (as defined in this current study) could be developed and a fuller picture of what participants went through would be discovered. Researchers conducting future studies on Aboriginal peoples' experience with TB should consider taking a holistic approach to how healthy families and communities provide strength, and support TB diagnosis and treatment. Further to this, directly gaining participant perspectives on practice and/or policy implication and how their TB experience could have been improved could lead to enhancements in practice and policy.

Tuberculosis is clearly a complex problem and while this study aimed to understand transmission at broad levels, it was not able to fully capture many issues that impact the high rates within some communities. These include the historical implications that continue to impact TB perceptions and feelings today. Furthermore, this study does not address issues such as crowded housing, poverty, and other chronic health conditions that have high comorbidity with TB. The interviews conducted with participants typically very early after treatment initiation and they had not returned home to continue treatment (with the exception of most of the Saskatchewan participants). As such, the impact of having to cross jurisdictional lines to be treated for TB is not fully explored, which is another significant policy consideration. This is important to explore, as a lack of seamless transition between provincial and federally funded services has negative impacts on Aboriginal peoples (National Collaborating Centre for Aboriginal Health, 2011).

An interesting finding from this study, which should be further explored, is related to how Aboriginal peoples from non-remote reserves who had access to health services in their communities and chose not to utilize them for a diagnosis. It would be interesting to understand if this was a circumstance of a lack of available diagnostic equipment or a lack of confidence in the services provided in their community. Furthermore, it will be important to conduct a longitudinal study with participants from the various community settings to examine treatment adherence after leaving isolation, integration back into their communities, if their family members were diagnosed with TB, and if stigma continued to impact their well-being. This research should be done with a sensitivity to how connections factored into this experience.

This study is one of the first to examine the TB experience for Aboriginal peoples living in various community settings across the Prairie Provinces. These findings make important contributions to the current body of literature on TB of Aboriginal peoples and communities. Important stories of the TB experience were shared by the Aboriginal participants as they navigated their illness and provided insights into the barriers and supports that TB patients currently face. The failure to recognize the large influence the broader system has on individual health leaves out important parts of the TB experience. This ultimately does a disservice to those suffering from TB, their loved ones, and their communities.

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