

**IMPACT OF INTER-COMMUNITY AND INTER-JURISDICTIONAL MOBILITY
OF FIRST NATIONS ON TUBERCULOSIS AND TUBERCULOSIS PREVENTION
AND CARE PROGRAMMING**

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By

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ABSTRACT

Tuberculosis (TB) rates are disproportionately higher among Indigenous people than Canadian-born, non-Indigenous populations, including in Saskatchewan. Among other factors, inter-jurisdictional mobility of First Nations people between Alberta (AB) and Saskatchewan (SK) may contribute to persistence of TB by disrupting prevention and care programming. This research explores the potential impact of inter-jurisdictional mobility of First Nations on existing tuberculosis prevention and care programs. Objectives include: (1) identify mobility patterns, (2) assess current policies covering First Nations TB prevention and care programming, and (3) evaluate the potential impact of inter-jurisdictional mobility on TB and TB programming. The study community is a remote First Nation community in northern Saskatchewan located near the Alberta border. I conducted semi-structured interviews with community participants around mobility patterns. A multi-level document review of TB prevention and care policies and interviews with healthcare providers in both provinces were also conducted.

Due to the rural location of the community, external mobility is frequent. Motivations include healthcare, work, family, entertainment, shopping, traditions, and others. Frequency and destinations of travel vary by season with inter-provincial mobility to Alberta being most common in the winter via temporary winter roads. Currently, there are no federal or provincial policies or procedures in place for mobile TB patients. However, health care workers follow a standard treatment procedure for mobile patients. Lines of communication between provinces and communities are clear but direct communication between communities is not, currently there is no prescriptive path of communication between jurisdictions. Without established policies, the possibility of treatment non-completion and failure may be increased, as patients may "slip through the cracks." Specific policies across jurisdictions are needed to address this. Clear policies and communication paths, and inter-jurisdictional coordination, can increase seamless care for mobile patients. This study supports the growing literature on TB among Indigenous populations and contributes to addressing mobility as a determinant of health.

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LIST OF ABBREVIATIONS

AB	Alberta
AHS	Alberta Health Services
CBPR	Community Based Participatory Research
CHR	Community Health Representative
CIHR	Canadian Institute of Health Research
CW	Clearwater River Dene Nation
DOH	Determinants of Health
DOT	Directly Observed Therapy
EHR	Electronic Health Record
FNIHB	First Nations Inuit Health Branch
IGRA	Interferon Gamma Release Assay
IRT	Implementation Research Team
LTBI	Latent Tuberculosis Infection
MHO	Medical Health Officer
NAAT	Nucleic Acid Amplification Tests
NCCIH	National Collaborating Centre for Indigenous Health
NITHA	Northern Inter-Tribal Health Agency
PHN	Public Health Nurse
SAT	Self Administered Therapy
SHA	Saskatchewan Health Authority
SDOH	Social Determinants of Health
SK	Saskatchewan
TB	Tuberculosis
TST	Tuberculin Skin Test
VOT	Video directly Observed Therapy
WHO	World Health Organization

CHAPTER 1:INTRODUCTION

This thesis explores the potential impacts of inter-jurisdictional mobility of First Nations people on Tuberculosis (TB) and care and prevention programming. TB has a long history in Canada, and while it has been studied extensively it continues to be a burden on certain populations, which includes some high incident Indigenous communities throughout Canada. Despite this research, jurisdictional mobility and its relationship to TB, in particular as a potential risk factor, has not been fully explored. This relationship may be especially important for communities that are in proximity to the boundaries between multiple health jurisdictions. This case study focuses on geographic mobility and its impact on TB programming in a remote First Nation reserve community near the Alberta (AB) and Saskatchewan (SK) border in Northern Saskatchewan.

1.1 RESEARCH CONTEXT

There are over 370 million Indigenous people worldwide and many are living in isolated areas with limited access to services and resources. For many this has led to generally poor health associated with overcrowding, malnutrition, disease prevalence and other factors (Jacquelin-Andersen & International Work Group for Indigenous Affairs, 2018). The higher burden of poor health and other disparities felt by Indigenous populations worldwide is also evident in Canada. In the Indigenous Services Canada's Departmental Plan for 2019 to 2020 Honourable Seamus O'Regan, Minister of Indigenous Services Canada states "We are focusing on improving access to health care and social services for Indigenous peoples, including through Jordan's Principle and the Inuit Child First Initiative." (Indigenous Services Canada, 2019). Improving health outcomes for Indigenous populations must be made a priority in order to decrease the unequal burden of poor health felt by Canada's Indigenous populations. TB is a disease with a colonial legacy that continues to impact Indigenous populations around the world, and within Canada.

The TB rate among Indigenous people in Canada is higher in comparison to Canadian-born

non-Indigenous peoples. Aboriginal¹ people in Canada are 5% of the total national population however they comprise about 50% of the total number of TB cases diagnosed among Canadian-born individuals (Long et al. 2013). Among these, Métis people accounted for 3% of total TB cases and First Nations people accounted for about 23% of all active TB cases in 2012 (Vachon et al., 2018a). There has been a steady decline of both the number and prevalence of First Nations people with TB in Canada since the mid-twentieth century. However, in recent years the decline has stagnated (Figure 1.1). This burden is not distributed evenly. Prior work suggests that most First Nation communities are free of TB while a minority of others are suffering from a sustained high incidence of the disease to such an extent that its presence has become normalized (Long et al., 2013). The full range of reasons contributing to this persistence has not been fully identified, however McMullin et al. (2013) emphasizes the importance of understanding the “causes of the causes” identified by Marmott (2005), known as the Social Determinants of Health (SDOH). McMullin et al. (2013) identify that marginalized communities often do not have resources for basic needs. The social hierarchy in communities can cause despair and if social efficacy is lacking it can disrupt people’s lives. As well, health deterioration caused by loss or trauma were found as “causes of causes” for continued TB in high incident prairie communities. One possibility that has yet to be considered fully is the role of mobility in TB transmission and treatment. Aspler et al. (2010) conducted a study on inter-jurisdictional transmission on TB in which they found that multiple cases of TB were from the same strain in which the patients were highly mobile with transmission over an area of 26,000km². First Nation communities are not isolated; rather, they are often connected to nearby communities by kinship networks. However, current jurisdictions, healthcare structures, and TB programming management may not account for mobility between jurisdictions. For the purposes of this study I

¹ Section 35 of the Canadian Constitution Act (1982) recognizes three distinct groups of Aboriginal people in the country; these include the First Nations, Metis, and Inuit. Of these, First Nations people comprise the largest group at 977,230 in 2016, which includes a 33.3% growth in population since 2006 (Statistics Canada, 2018). Currently, there are 634 First Nation communities or reserves in Canada and are diverse with over 50 different nations and languages. “Aboriginal” is the term recognized under federal legislation within the Canadian Constitution Act of 1982. However, “Indigenous” is becoming more standard which allows international and global recognition of Indigenous peoples. “Indigenous” is formally recognized within the United Nations Declaration of the Rights of Indigenous Peoples, which Canada endorsed and acknowledged as a responsibility to the Indigenous peoples of Canada.

explore how travel (and subsequent contacts), combined with policy and programming failures, may help to sustain the presence of TB rates.

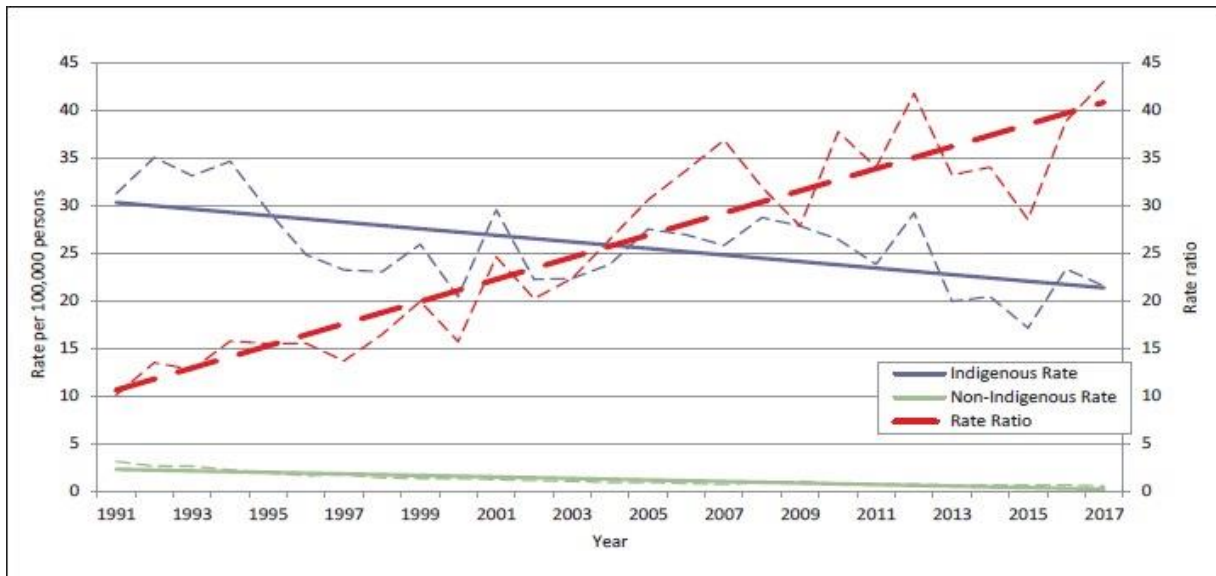


Figure 1.1: Reported TB incidence rate by population group from 1991 to 2017 (Long et al., 2019)

TB is a communicable disease caused by infection with *Mycobacterium tuberculosis*. The most common form of TB is pulmonary in which the bacterium enters the lung through inhalation of droplet nuclei exhaled by an infected person via the aerosol route. Although less common, TB has been known to affect many other parts of the human body, including the skin, lymph nodes, the spine, and, in rare cases, the brain. If the host’s immunity is inadequate to stave off infection, then the bacteria will replicate, doubling in number every 24 hours (Canadian Lung Association et al., 2014; Iseman, 2000). *M. tuberculosis* transported via aerosolized droplets may be transmitted to others through coughing, speaking, or singing. The physiological impacts and symptoms of TB are further explored in chapter two of this thesis.

The World Health Organization (2014) has set a goal of eradicating TB by 2050. In order to achieve this, the full range of factors influencing TB transmission and persistence needs to be better understood. From the early 20th century it has been well understood that TB is not only a biomedical disease, but also a disease with a historical and social identity² (Grzybowski & Allen,

² In the early twentieth century, famed medical practitioner Dr. William Osler wrote that “TB is a social disease with a medical aspect.” (Grzybowski & Allen, 1999).

1999; Long, 2007). Existing studies have looked at a broad range of causes of health disparities and social inequities among Indigenous populations such as socioeconomic status, education, and overcrowding that can contribute to the high levels of TB (Butler-Jones & Wong, 2016; Canadian Lung Association et al., 2014; Hargreaves et al., 2011). Colonization is an important determinant of health that impacts Indigenous populations, this is further explored in the next chapter (Greenwood et al., 2015; King et al., 2009; Wien & Reading, 2009). Health disparities facing Indigenous populations are a result of previous government policies and colonial health practices imposed on Indigenous populations (Henderson et al., 2018; Truth and Reconciliation Commission of Canada, 2015). Equally, TB is seen as a legacy of colonization and historical oppression of Indigenous peoples in Canadian society as we see in Chapter 2 (Moffatt et al., 2013; Møller, 2007). One factor that has received little attention, but which nonetheless may play a role in the inequitable occurrence of TB among Indigenous people in Canada, is the movement of people through space, an element of human activity that is understood by geographers as a fundamental component of human health. Historically, mobility and migration patterns have played an important role in health and have been found to be both beneficial and detrimental to human health in the case of infectious diseases depending on circumstances, with respect to both transmission and access to health care (MacPherson & Gushulak, 2001). TB researchers have called for more studies of the effect of mobility on the disease among Indigenous people (Alberta Health and Wellness, 2010; Rhoades et al., 2005; TB Partnership Working Group, 2013). Despite this, scant consideration has been given to mobility as a driver of TB risk; only one study to date has reviewed the implications of contemporary migration on health care accessibility among Indigenous people in Canada (Snyder & Wilson, 2012). In this study the authors explored mobility of urban Indigenous populations and found that migration directly impacts healthcare utilization. Moreover, mobility and geographical location are not considered within the determinants of health (DOH) in the current Canadian framework (Government of Canada, 2019b). Mobility and geographical location as DOH may help inform policy and needs to be further explored.

Beyond the lack of research, the literature highlights a separate issue: a lack of clarity over what constitutes mobility. Indeed, although fundamentally different in terms of process and motivation, mobility is not generally differentiated from migration in the literature. Both mobility and migration refer, generally, to the movement of people, but they carry disparate

meanings. The operational definition of **migration** I use in this study includes persons who have moved to a different community or region with a change in residence (Amorevieta-Gentil et al., 2016). Distinct from this, the operational definition of **mobility** is the temporary movement out of a home community of residence. Mobility can be further broken down by its duration, including short-term and long-term mobility (Moreno et al., 2017). For this study, I classify short-term mobility as travelling out of community of residence for a week or less. And long-term mobility as travelling out of community of residence for more than a week (up to a month and less than a year). This research focuses on mobility rather than migration and works towards understanding patterns and motivations of mobility, and its potential effect on TB incidence in high incidence communities.

1.2 RESEARCH OBJECTIVES

Major anti-TB strategies, including the SK TB Strategy, the Canadian TB Strategy, and the Strategy Against TB for First Nations on Reserve, all identify mobility and continuity of care across jurisdictions as a phenomenon that requires further clarification (Health Canada, 2012; Canadian Lung Association et al., 2014; Saskatchewan Health Authority, 2018). Therefore, the overall purpose of this research is to determine the impact of inter-jurisdictional mobility of First Nations people on TB prevention and care programs, focusing on Canada's Prairie Provinces. To do this I carried out a case study with the following objectives:

- I. Identify mobility patterns of on-reserve First Nations in a border community;
- II. Assess relevant TB care and prevention programs with a focus on jurisdictional issues; and,
- III. Assess the potential for inter-jurisdictional mobility to drive transmission based on mobility patterns and TB policy.

Based on these objectives, I seek to answer the following research questions. What are the major motivations for mobility and patterns of mobility of an on-reserve First Nation community located near a provincial border? What are the gaps in TB programming and policy regarding mobile patients? What is the potential relationship between TB and mobility?

This research is carried out under an umbrella project called *Implementing the “Patient’s Charter of Tuberculosis Care” in high incidence Indigenous communities and across jurisdictional borders*³. The Canadian Institutes of Health Research (CIHR), through its Institute of Indigenous Peoples Health (IIPH), developed a strategic funding initiative aimed to support research designed to eliminate identified disparities in health outcomes between Indigenous and non-Indigenous Canadians in four exemplar areas. Those exemplars were: mental wellness, oral health, diabetes and obesity, and TB, and funding was administered through several programs. One such program was an open operating competition - Pathways to Health Equity for Indigenous Peoples Health (hereafter, *Pathways*) for Implementation Research Teams (IRTs). My own research is situated within the broader goals of one of these IRTs holding *Pathways* funding in the TB exemplar. IRT funding supported teams and their work in three separate competitions: Components 1, 2, and 3. The first component was a team-building grant to support relationship building efforts between IRT members and community partners. The second component was an intervention phase that executed two community-identified interventions that were believed to deliver on a reduction in local TB incidence while at the same time promoting community wellness. The third component will expand the project geographically to other high TB incidence settings in Canada, namely Northern Manitoba and Nunavut. While the project is moving into its third component, my research took place during the second component of *Pathways*. By understanding the current state of TB policy and programming nationally, regionally, and provincially, and creating an image of mobility within border communities, I hope to articulate the importance of clear communication between jurisdictions, and the existing potential for breakdowns in the chain of TB prevention and treatment. In turn, this information may be used to inform new policies designed to move towards our goal of eliminating TB by 2050 and decreasing existing disparities in health among Indigenous populations.

1.3 POSITIONALITY

I first became interested in research in healthcare, disease, and vulnerable populations through my undergraduate degree and electives in my last year of study. The major turning point

³ With Dr. Richard Long of the University of Alberta as principal investigator. CIHR grant numbers: RN246253-337694, RN298107-379492. The current research was funded under SHRF.

was an “Environment and Health” course that showed the importance of DOH and inequities faced by First Nations populations. Due to the qualitative nature and community-based aspects of this research, my position as a researcher and reflexivity are important. Reflexivity is the process of continuing internal dialogue and self-evaluation of a researcher’s positionality (their identity) and the recognition of this position’s impact on research and outcomes (Berger, 2015; Bradbury-Jones, 2007). Thus, it is important for me to understand how my positionality impacts the current research and to explain my personal position here. Personal characteristics such as gender, race, age, sexual orientation, immigration status, experiences, language, beliefs, and biases have been identified as affecting a researcher’s lens when carrying out research. Along with personal characteristics, being mindful of power asymmetry during interviews and the research process is essential (Berger, 2015; Kvale & Brinkmann, 2009). I am currently a student at the University of Saskatchewan, I began my academic journey in Physiology and Pharmacology. While this provided the structure required to understand the biomedical aspects of TB, my experiences in community and my graduate studies have provided me with the basic knowledge of community research and various disparities faced by Indigenous populations. It has also led me to take on a partnership with the research community, and to understand the relationship between community members and myself. However, I was not familiar with practices of decolonization and the complexities of First Nations cultures when I first began my graduate studies program. My master’s program, then, has been both an academic journey and one of self and societal-reflection.

I learned the basic history of colonization of Indigenous peoples in Canada during my elementary and high school years in Saskatoon, Canada. In order to further my knowledge of First Nations cultures as a graduate student I participated in community outreach events, Treaty Days, and volunteered in schools in Clearwater River Dene Nation (CW). I adopted critical reflexivity throughout my research and kept a reflective journal to keep track of all community visits. In the journal and through self reflection, I analyzed my relationships with the community and how it may influence the data. My personal characteristics may have influenced the way participants and community members reacted and spoke to me, as well influenced my approach in the community.

My family and I moved to Saskatoon in 2006. For much of my young days, I was raised in Sri Lanka, and as a young woman of color heading into rural communities, I noticed people's reactions to me often began with the question of where I am from. I believe this may have helped decrease some power imbalances that may exist between me, the researcher, and community members. As a member of a country impacted by colonization, this was a point of commonality for both community members and me. My darker complexion was a point of conversation and acted as an ice breaker. International medical doctors and nurses are common in remote communities, so I was often mistaken as a health provider in the community. Being mistaken for a nurse or doctor led to many conversations about their health even after correcting the misconception. This may have also led to some community members hesitating to approach me due to mistrust of the healthcare system and personnel. I was raised with Buddhist and Sri Lankan beliefs that are different from both Western and Indigenous ideologies. While my culture is very different from Western culture, I often noticed the parallels between my cultural upbringing and Indigenous worldviews. Family and community are central in both cultures, and the idea of home is rooted in kin networks. I was raised with a great emphasis on respect for the elderly, which is an important aspect I noticed in CW. Having these parallels and similarities I believe helped me build a stronger relationship with the community.

Along with my ethnicity and upbringing, I believe my age and gender may have also influenced community participants' reactions to me. It is possible that the community members who approached me for interviews were, as a whole, more female than male because of my own gender as a female and being in my early 20s. Moreover, my identity as a researcher is not independent from those who have carried academic research with the community before. The Pathways project has been working with the community for many years, and this especially helped make my introductions into the community easier. As well, many women are involved within the project in the community, which may have been a reason for community member interviews being with more women than men. My positionality, personal characteristics, cultural differences, and the western education system in which I grew up in frame the lens that I use to carry out my research and has the potential to limit the effectiveness of my research. I believe that by recognizing my potential biases, through critical reflexivity throughout the research I am able to better approach objectivity in my research.

1.4 THESIS ORGANIZATION

This thesis is presented in six chapters including this introductory chapter. Chapter two situates the research in related literature about First Nations populations of Canada, TB and its determinants, and current studies on mobility and its impact on health. Chapter three describes the research methods that I employed to conduct this study. Chapter four presents results found on mobility and the role of land and home in the partner research community. Chapter five explores the current state of TB care and prevention programming. I analyze the potential impact of mobility and current programming for mobile patients. The thesis presents potential recommendations for inter-jurisdictional programming and mobility. Finally, I explore the major contributions and potential future directions of this research.

CHAPTER 2:LITERATURE REVIEW

Tuberculosis is an infectious disease that disproportionately affects the Indigenous populations of Canada. Several factors, such as socioeconomic status, overcrowding and others have been linked to higher than average incidence of TB among Indigenous peoples in Canada (Canadian Lung Association et al., 2014; Hargreaves et al., 2011). However, one factor that has not been considered fully is the geographical mobility of people. Migration and mobility play an important role in health, and the potential impact of these phenomena need to be considered further regarding TB. This chapter presents an overview of First Nations in Canada, TB, and mobility research. The first section explores First Nations in Canada, social determinants and the differences there may be with Indigenous determinants of health. The next section is an analysis of TB as a disease, its origins in Canada, epidemiology, and risk factors. The third section of this chapter explores the current state of knowledge of Indigenous mobility, and its role in health and healthcare. The last section presents a current research gap in mobility and TB.

2.1 FIRST NATIONS PEOPLE OF CANADA

First Nations have been and are still fundamentally impacted by harmful colonial systems of power. To understand colonialism in a modern context, I first dive into the history of colonialism in Canada. Colonialism is defined as the establishment of foreign rule over a territory and the control of its people, in addition, settler colonialism is the process of colonialism in which the settlers seek to replace the original population of the territory (LeFevre, 2015). In the context of Indigenous peoples in Canada, colonization led to loss of traditions, culture, ways of knowing and much more (MacDonald & Steenbeek, 2015). First Nations were self-governing peoples until the settlement and colonization by European settlers. Between the 1500s and 1600s, European settlers pushed in throughout North America and established colonies. The British and French created alliances with First Nations for the fur trade and other interests. The 16th and 17th century consisted of power struggles between the French and the British, and thus military relationships with First Nations were vital. In 1725 a “Peace and Friendship” treaty was created between the British and First Nations in the east coast of Canada which included Mi’kmaq and Abenaki peoples (Daschuk et al., 2006; Government of Canada, 2018; Wicken & Reid, 1996). However, with the British and French still at conflict, First Nations

were divided between supporting these two major colonizers. The Indian Department was created by the British in 1755. Then, between 1756 to 1763, the Seven Years' War continued and at the end the Treaty of Paris was signed. With the French retreating, Britain became the majority power and the treaty process was formalized by the Royal Proclamation of 1763. Following the Royal Proclamation of 1763, precipitated by the American War of Independence in 1783 and the War of 1812, relationships began to shift from the British relying on Indigenous peoples and their knowledge as allies to an assimilationist perspective. Indigenous peoples' lands were taken away as immigrant numbers increased. By the late 1800s bison were becoming extinct in western Canada, and many First Nations lacked food security. Canada as it became an independent nation in 1867 inherited all treaty obligations that were signed between First Nations and the Crown. Soon after, the numbered treaties began to be created from 1871 to 1921 (Daschuk et al., 2006; Government of Canada, 2018; Miller, 1996; William, 2018).

Along with the numbered treaties, the Indian Act was consolidated from separate colonial legislation. The Indian Act was enacted in 1876 and only recognizes First Nations of Canada or colloquially "Indians" at the time of creation but not Métis or Inuit peoples. The Indian Act was first created in order to assimilate First Nations (Assembly of First Nations, n.d.; Canadian Charter, 1982; Indian Act, 1985; Montpetit, 2011). Reserves, tracts of land upon which First Nations were permanently settled, were created under the Indian Act as a way to "civilize" First Nations by restricting mobility, introducing agriculture, and enforcing Christianity. In 1867 churches were given control over First Nations education which led to the formation of residential schools in the 1880s. These schools removed children from communities and families, many of whom faced sexual, physical, mental, and emotional abuse (Indian Act, 1985; Miller, 1996; Milloy & McCallum, 2017; Waldram et al., 2006). The impacts of residential schools and colonial practices are still felt today and have led to deep rooted intergenerational trauma that continues to shape the health and wellbeing of First Nations people (Greenwood et al., 2015). Over the course of this history, diseases such as TB were introduced to First Nations by European settlers or were exacerbated by colonial forces. This relationship is explored further throughout this chapter.

2.2 WHAT IS TUBERCULOSIS

TB is a communicable disease caused by *Mycobacterium tuberculosis* and the most common form of TB is pulmonary. Once infection has taken hold, TB can present as latent tuberculosis infection (LTBI) or, eventually in some cases, active TB (in about 5-10% of cases). Active pulmonary TB is most likely to show lung cavitation (gas-filled spaces in the lung) and may erode into the bronchi. The normal symptomology of active TB infection includes persistent cough, fever, night sweats, chest pain and other symptoms, and these symptoms may be used to diagnose the disease. Patients with LTBI are largely symptom-free and are unable to infect others. However, when immune competency of an individual declines LTBI can transition from latent to active disease through reactivation (Canadian Lung Association et al., 2014). Activation of TB can be triggered by several different risk factors, explored later in this chapter.

TB has a long history in Canada and around the world. An early progenitor of *M. Tuberculosis* presented in East Africa over 3 million years ago. The modern forms of *Mycobacterium tuberculosis* may have originated 20,000-15,000 years ago. (Daniel, 2006; Iseman, 2000). There is some evidence from mummified remains that show that diseases that resemble TB may have existed before European contact (Gerszten et al., 2012; Raff et al., 2006). Some research suggests that a TB epidemic that started some 300 years ago was brought by European settlers and further fueled by the interruptions to lifestyle and deteriorating health (Daschuk et al., 2006; Grzybowski & Allen, 1999). In Canada, sanatorium treatment was first made available in 1897 where people were isolated, given fresh air, food, rest and rehabilitation. However, treatment was not equally provided to Indigenous populations in Canada until much later. Indigenous populations have a different history with TB in Canada (Grzybowski & Allen, 1999; Lux, 2016).

2.2.1 Origin and History of Tuberculosis Among First Nations People

History provides key context for understanding the contemporary TB situation within Canadian society. TB may be the legacy of colonization and historical oppression of Indigenous peoples in Canadian society (Daschuk et al., 2006; Grzybowski & Allen, 1999; Moffatt et al., 2013). Historically, First Nations have had negative experiences due to forced sanatorium admissions, infection in residential schools, patient isolation, and lack of proper TB treatment

and healthcare on reserves (Hackett, 2005; Wherrett, 1977). Arrival of Europeans into Canada led to the introduction of new infectious diseases to First Nations, likely including new strains of TB (Waldram et al., 2006). Following policies put in place by government and the churches towards the end of the 19th century and into the 20th century, a TB epidemic arose among First Nations. This epidemic was caused by and exacerbated due to a lack of food and lifestyle changes including the implementation of reserves and residential schools (Daschuk et al., 2006; Milloy & McCallum, 2017). Nevertheless, it was only during the 1940s that the federal government of Canada, through the Department of Indian Affairs, made a concerted effort to eliminate TB in residential schools. Initially this was centred around removal of active cases to sanatoria for treatment, followed in the 1950s with antibiotic therapy which proved more successful overall. Nevertheless, a failure to obtain true consent of patients before removal from communities and a tendency to place blame on individuals, as well as the debilitating effects of early surgical treatments led to stigmatization of those with TB, and a reluctance among some to talk about the disease. The effects of these unjust treatments and effects persists into the present (Gibson et al., 2005; Greenwood et al., 2015; Hackett, 2005; Komarnisky et al., 2016; MacDonald & Steenbeek, 2015). Understanding these historically negative experiences allows us to understand the mistrust of the medical system, stigmatization of the disease, as well as contemporary patterns of epidemiology of TB within Canada for Indigenous populations and specifically First Nations populations.

With the discovery of antibiotics for TB beginning in the 1940s, which became commonly administered the following decade, TB rates in Canada declined, including among Indigenous peoples. By 1970, TB incidence among Indigenous peoples had been in consistent decline for three decades; however, these declines lauded by Dr. Wherrett in the late 1970s were not sustained. Between 1970 to 2010, although the Canadian born non-Indigenous proportion of active TB cases dropped from 67.8% to 11.8%, the proportion of active TB cases among Indigenous populations in Canada increased from 14.7% to 21.2% (Canadian Lung Association et al., 2014). Here again the burden is not felt equally, as this increase is also localized to certain geographic locations and some, but not all, Indigenous communities may be classed as high incidence. In a recent review of the global TB burden, it was found that in middle and low-income countries Indigenous people bear a higher rate of TB than the national average, a pattern that is also found in Canada (Komarnisky et al., 2016). The recent increase of TB rates per

100,000 and unequal burden faced by Indigenous people, indicate that there is a need for more localized assessments of the ongoing causes of TB among Indigenous populations (Vachon et al., 2018b). Of the Indigenous peoples in Canada, TB rate in First Nations populations has sustained at a stable rate between 2001 to 2010 with no reductions (Canadian Lung Association et al., 2014).

2.2.2 Epidemiology of Tuberculosis in First Nations People

First Nations people living in specific high incidence and geographically isolated communities comprise a large proportion of TB-affected individuals. First Nations living on-reserve in Canada have a TB incidence rate of 34.1/100,000 compared to a First Nations living off-reserve rate of 14.1/100,000 (Vachon et al., 2018b). These cases are not evenly distributed, either by geography or group. For instance, it was found that over half of the TB cases found in Indigenous populations across the prairie provinces (AB, SK, Manitoba) were among “Registered Indian” and Métis populations (Long et al., 2013). Understanding these patterns and the heterogeneity of TB cases among First Nation communities is a critical step towards improving TB care and prevention programming and the overall understanding about this complex disease. Provincially, TB in Saskatchewan has been stable over the last 10 years at a rate of about 7/100,000 (Public Health Agency of Canada, 2016). However, here too the burden is felt unequally. Of the total number of cases 54% are found among First Nations people living in Northern Saskatchewan⁴. The higher distribution of TB cases in Northern SK is indicative of risk factors associated with TB that are present in some communities but not others. Some of the factors that contribute to this heavier burden and the persistence of the disease are well documented and relate to DOH (Abonyi et al., 2017; Gibson et al., 2005; Moffatt et al., 2013; Møller, 2007; Pedrazzoli et al., 2017). Others are yet unknown and may also include the nature of northern migratory and mobility patterns which are explored throughout this chapter.

⁴ Northern SK according to the Saskatchewan Health Authority health networks zones accounts for North West, North East, and Athabaskan Health Authority as depicted in Figure 2.2, pg. 25.

2.2.3 Tuberculosis Risk Factors and Determinants of Health

Collectively, the SDOH is a set of social and economic conditions (rather than individual behaviors) which are thought to influence individual and population health outcomes and even how long we may live. These determinants are in turn a subset of the broader DOH, which includes environmental conditions and a person's individual characteristics and behaviours (including genetic endowment). The DOH can also provide a useful framework for understanding why TB incidence can vary significantly between populations or communities. The DOH emerged out of the 1974 Lalonde Report of Canada, entitled *New Perspectives on the Health of Canadians* (Lalonde, 1974). The Lalonde report is significant as it was the first step taken towards Health Promotion in Canada and began the process of creating a framework for understanding health determinants. The Lalonde framework identified four major components, human biology, health care systems, environment, and lifestyle, that impact health. These four determinants grew to 12 by 1996 (Canadian Public Health Association, n.d.; Glouberman & Millar, 2003).

Although they share a common rationale, there is no single set of determinants recognized universally. Notably, Health Canada recognizes 12 determinants (Table 2.1) (Government of Canada, 2019a). These determinants do not work in isolation but are interconnected and the interplay between the factors has an important influence on health. Within the DOH framework, SDOH are specific groups of social and economic factors that impact populations. Additionally, structural determinants are conditions that create or reinforce social hierarchy that lead to unequal SDOH distribution. Structural determinants such as high levels of population migration and increased urbanization can lead to unequal distribution of social determinants of TB due to weak health systems and poor access in rural communities (Hargreaves et al., 2011; Pedrazzoli et al., 2017). There are several different DOH frameworks, each reflecting key factors such as poverty, overcrowding⁵ (Pepperell et al., 2011), and stress, that contribute to higher incidence of TB (Canadian Lung Association et al., 2014; Gracey &

⁵ For instance, reserve communities tend to have higher level of overcrowding which is undoubtedly a contributing factor to the higher rates of TB in northern Saskatchewan (Patterson & Dyck, 2015).

King, 2009; Hargreaves et al., 2011). These determinants, then, may be instructive with regard to population-level variations in rates of TB.

Common population-level and environmental characteristics identified for TB include malnutrition, food insecurity, poor housing, overcrowding, environmental conditions, and access to resources and healthcare. These characteristics can influence TB pathogenesis by increasing exposure to active TB and may also advance progression to active disease. Insufficient access to resources and healthcare can lead to lack of diagnosis and poor treatment success (Canadian Lung Association et al., 2014; Hargreaves et al., 2011; Schmidt, 2008). While urbanization has been considered as a factor influencing TB rates, geographic concepts related to space and movement, including mobility and geographic isolation, have not found their way into models of the DOH (Pedrazzoli et al., 2017). These factors, too, may need to be included when attempting to account for variations in TB, as they may contribute to higher burdens of TB. Although the 12 DOH identified by Health Canada are broad (Government of Canada, 2019b) (Table 2.1), the current DOH models fail to encompass the direct impact of geographical concepts such as space and place on health, and so might well be expanded to include, at the minimum, the role of mobility in determining health status.

Table 2.1: Determinants of Health Canada (Government of Canada, 2019b)

1. Income and social status
2. Employment and working conditions
3. Education and literacy
4. Childhood experiences
5. Physical environments
6. Social supports and coping skills
7. Healthy behaviors
8. Access to health services
9. Biology and genetic endowment
10. Gender
11. Culture
12. Race and Racism

2.2.4 Indigenous Determinants of Health

The DOH framework identified by Health Canada is applicable to diverse populations in Canada, however due to differences in worldview, history, the impact of colonialism, and the

unequal distribution of resources that affect Indigenous people it is important to understand DOH from an Indigenous point of view. While race and racism are included in the DOH, a major criticism of the frameworks for Indigenous populations is the lack of consideration of colonialism (Greenwood et al., 2015). Indeed, Indigenous peoples worldwide are profoundly impacted by the destructive impacts of colonialism, the roots of which may lie in the distant past. Another criticism is that the bulk of the continued writing about Indigenous health has been framed by non-Indigenous scholars. Conversely, the Indigenous DOH has been framed by Indigenous health scholars, and provides a level of explanation that is separate and more appropriate in this context than the 12 determinants of health identified by health Canada.

Although there is not a singular framework or model for Indigenous Determinants of Health, the National Collaborating Centre for Indigenous Health (NCCIH), a national Indigenous organization, introduces DOH in an Indigenous context. For the purposes of this research, I focus on the Integrated Life Course and Social Determinants Model of Aboriginal Health introduced by NCCIH and the *“Determinants of Indigenous Peoples’ Health in Canada: Beyond the Social”*(Greenwood et al., 2015).

NCCIH draws on distal, proximal, and intermediate levels of DOH within an Indigenous context. Proximal determinants include social, historic, and economic contexts such as health behaviours, physical environments, employment and income, education, and food insecurity, which all have a direct impact on physical, emotional, mental and spiritual health. Indian and Northern Affairs Canada found that Indigenous communities represent 65/100 of the unhealthiest communities. Health behaviours such as alcohol use, smoking and others have been linked to poor physical, emotional and intellectual development in Indigenous children. Physical environment is a key player in health of populations, overcrowding, poor housing quality, homelessness, and other detrimental aspects of physical environment are prevalent among First Nation communities. Intermediate determinants include systems, which represent the origin of proximal determinants. First Nations people living on-reserve are under a federal system of health which has problems of overlapping or conflicting jurisdictions and a severe limitation in access and delivery. In addition, the multiple jurisdictions and fragmentation of the healthcare system in Canada results in isolating and managing issues such as addiction, suicide, poor housing and unemployment separately rather than collaboratively (King et al., 2009).

Distal determinants of health represent economic, political and social determinants that are the root of both intermediate and proximal determinants. For First Nations populations distal determinants include colonialism, racism, and suppression of self determination which represent the root of unequal distribution of disparities faced by First Nations in Canada (Greenwood et al., 2015; Wien & Reading, 2009). Due to the interaction and existence of complex determinants that are specific to Indigenous life and histories it is important to consider diseases through an Indigenous way of knowing.

The Integrated Life Course and Social Determinants Model of Aboriginal Health includes the stages of life, SDOH, and socio-political contexts as connected to one another in spheres. There is an emphasis on the interconnectedness of all aspects of life with health. “Proximal, intermediate, and distal social determinants are filtered through socio-political contexts, life stages, and health dimensions.....to shape overall wellbeing” (Wien & Reading, 2009, pg. 26). These frameworks may be extended with further consideration. The role of land is an important aspect of many First Nations cultures, and colonial forces and historical events have reduced access to traditional lands. Thus, Sarah de Leeuw calls for geography as a determinant of health due to the importance of place and land to Indigenous peoples (Greenwood et al., 2015). Building on this, it may be warranted to extend the discussion of geographic determinants to ways in which people move through space, whether with regard to spatial patterns or duration and timing (Figure 2.1). Figure 2.1 is an extension of the NCCIH model accounting for changing geographies in an individual’s life. First Nations people (and communities) do not exist sedentarily but exhibit complex patterns of mobility which in turn may affect their life situations and potentially their health. In the case of TB, it is possible that peoples’ movements may play a role in TB prevalence in some communities, particularly with respect to opportunities for transmission or perhaps modifying access to health care.

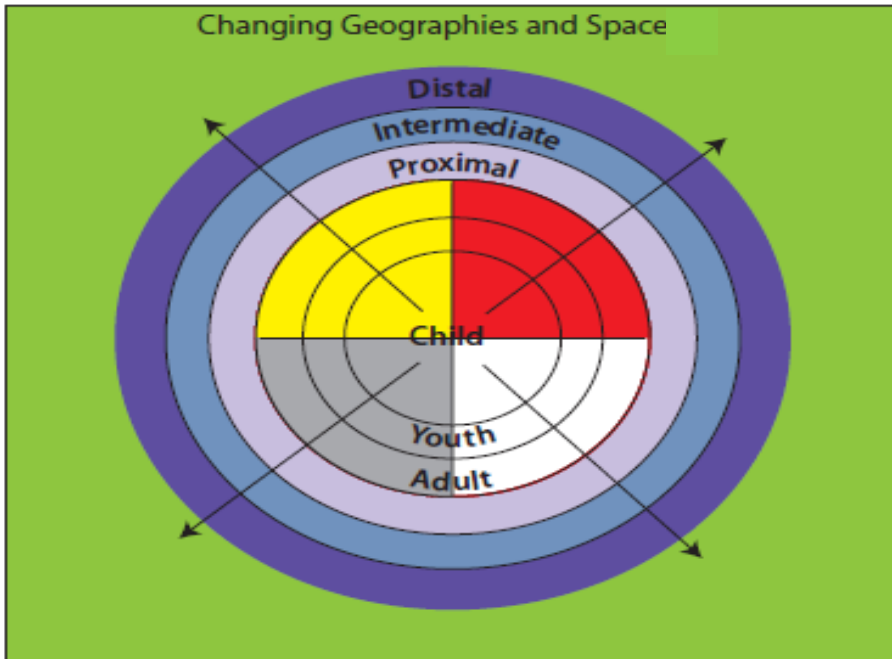


Figure 2.1: Model depicting Indigenous determinants of health and changing geographies (Based on the NCCIH Integrated Life Course and Social Determinants Model of Aboriginal Health).

2.3 WHAT IS MOBILITY?

The related concepts of mobility, migration and movement are often not clearly defined in the literature and are sometimes used synonymously to refer to a change of residence (Cooke & O’Sullivan, 2015; Cummings, Mohle-Boetani, Royce, & Chin, 1998; FitzGerald, Wang, & Elwood, 2000; Snyder & Wilson, 2012). Moreover, mobility, movements and travel are also at times used synonymously to define short-term geographic movement that does not include a change in residence (Moreno et al. 2017; Rhoades et al. 2005). For the purposes of this study it is critical to clearly define and differentiate these terms as the status of the individual traveler may affect the possibility of TB prevention and care in the new location. As stated earlier, migration is defined as a change in residence or community (Amorevieta-Gentil et al. 2016). Mobility, although used interchangeably with migration in some studies, is defined here as short-term (out of the community for one week or less) or long-term (absence for longer than one week and up to a month) temporary geographical movement, similar to how the term was used by Moreno et al. (2017). While motivations for mobility may vary, it is especially relevant regarding First Nations of Canada who reside outside of major communities and who may leave

the community frequently due to traditional mobility patterns tied to spatially-diffused familial relationships as well as the need to access resources that are unavailable in the home community.

2.3.1 Patterns and Motivations for Mobility

Historically, First Nation communities have tended to incorporate high degrees of mobility within their seasonal cycles, and many current First Nations people continue to pursue interests that take them from their home communities (Cooke & BéLanger, 2006; J. Taylor & Bell, 2004). This is true of First Nations in Saskatchewan; for example, in historical accounts the Dene people in what is now Saskatchewan followed the movement of the caribou (and other resources) seasonally and were thus highly mobile. The traditional travel routes used for hunting may still be used today by some members (Bone et al., 1973; McMillan, 1988; Parlee et al., 2010). It is important to understand that each First Nation may have unique spiritual connections to the land, and the specific spiritual connections to land are not homogenous in all First Nations traditions. However, in general First Nations have a sense of responsibility (stewardship) towards the land. Traditional knowledge, cultural practices, language and oral traditions are connected to and built from land (Greenwood et al., 2015; Mashford-Pringle & Stewart, 2019). These traditional motivations and patterns of mobility may offer insights into contemporary mobility patterns. Many people continue to pursue traditional activities including hunting, fishing and gathering while other, less traditional, circumstances, carry them to other communities. In all these cases the existence of provincial boundaries created by settler governments may be irrelevant with respect to the patterns of Indigenous mobility.

The motivations driving contemporary migration and mobility patterns are complex and can reflect forces and processes operating at multiple scales. Beyond those affecting the general population, Indigenous people may have additional reasons for mobility as well as different mobility and migration patterns due to cultural, social, and historical differences. Modern migration and geographic mobility studies analyze motivations for mobility based on push and pull factors. Push factors can be defined as forces driving the individual to leave the current residence while pull factors are attractants, defined as perceived or actual benefits gained from the new location or residence (Clatworthy & Norris, 2007; Ristock & Passante, 2010). A third class of factors, stick factors, may work against the push and pull factors. Stick factors are those

positive community attributes that encourage an individual to remain in their community, even with push and pull factors compelling a move away. Finally, stay factors are reasons that discourage an individual from moving back to a community once they have migrated (Padarath et al., 2003).

In the literature, stick and stay factors are mainly used in migration studies. However for the purposes of this study I use stick factors as reasons for remaining in the home community while continuing to be intermittently mobile for both short and long periods of time, instead of migrating to a new destination (Oberoi & Lin, 2006). Stick factors such as language, culture, personal circumstances such as family obligations and age, and social factors may be a common reason for not migrating out of a community despite existing push and pull factors (Tjadens et al., 2013). These “push and pull” and stick factors may be different for different populations based on their experiences or their needs.

Finally, with mobility studies, it is also important to understand an individual’s activity space. An activity space may be defined as the local area in which people move or travel during their daily activities, otherwise known as the day-to-day space, and it is one measure of mobility (Sherman et al., 2005). The spatial extent of the activity space is not consistent across, or within, populations, but can be influenced by, among other things, access to vehicles, the age of the individual, their socioeconomic status, and other factors. In a rural First Nation border community, healthcare opportunities, resource distribution and access to essentials may also influence an individual’s activity space.

With increasing Indigenous urbanization, the motivations and push/pull factors resulting in migration and mobility may have shifted. This is reflected in the available research; the majority of current studies of Indigenous mobility tend to focus on migration due to urbanization rather than short-term or long-term mobility patterns (Clatworthy and Norris 2007; Senese and Wilson 2013). Common migration push factors out of home communities identified for Indigenous populations include poor socioeconomic status, lack of access to health facilities, unstable political situations, lack of educational opportunities, and violence. Pull factors to destinations of travel identified for Indigenous populations include community, family, traditional and cultural practices, and language (Clatworthy and Norris 2007; Ristock, Zoccole

and Passante 2010). Few studies in Canada have looked at **mobility** in the context of Indigenous people, and the majority of the research done on short term mobility of Indigenous peoples has taken place in Australia (Memmott et al., 2006; Proud, 2008). There, a common motivation for mobility is kinship networks. Accommodations are provided by families and due to crowded housing conditions on reserve this may act as a risk factor for TB. Another common motivation for short term mobility is access to resources. Memmott et al. (2006) studied Indigenous mobility in rural and remote Australia in which they examined the frequency and temporal patterns of short-term mobility. It was found that two to three days or less is common for short term mobility out of communities. Indigenous and social events were revealed to be a major reason for short term mobility.

For First Nations studies in Canada there appears to be a similar gap, as no studies have specifically looked at the modern patterns and motivations of geographic **mobility**, as defined earlier in this review; instead they have focused on **urbanization** and **migration** (Amorevieta-Gentil et al., 2016; Cooke, 2002; Cooke & Bélanger, 2006; Cooke & O'Sullivan, 2015; Peters & Robillard, 2009). Motivations for migration identified for First Nations are similar to that of overall Indigenous populations. One of the most common motivators for migration identified in First Nations is housing availability and overcrowding. First Nations on reserve have access to housing, however the availability of housing on reserves is scarce and often have long waitlists (Patterson & Dyck, 2015). As a result, migration into reserves due to housing is often gendered (Amorevieta-Gentil, Bourbeau and Robitaille 2016). Education and employment were major factors identified as a push factor driving migration out of reserves, while family and personal connections were identified as stick factors for migration back to reserves. Reserves are treated as a place of refuge and cultural identity, and a place away from racism and discrimination (Amorevieta-Gentil, Bourbeau and Robitaille 2016; Peters and Robillard 2009). While there is a lack of studies that look at geographic mobility, the patterns found regarding migration may also be applicable to mobility.

Closer to the subject of the present study, Clatworthy and Norris (2007) found that contemporary migration may be a continuation of traditional mobility. Short-term mobility is connected to several factors, including work, education, traditional ceremonies, and returning to family (Memmott & Australian Housing and Urban Research Institute, 2004; J. Taylor & Bell,

2004). Therefore, contemporary mobility and migration patterns could be a continuation of traditional mobility along with contemporary factors such as increased urbanization or kinship networks connecting different communities (Clatworthy and Norris 2007; Snyder and Wilson 2012). Despite this, further research is needed in order to understand motivations and patterns of contemporary short-term mobility among First Nations populations.

Contemporary mobility may be impacted by the imposition of colonial boundaries such as treaty boundaries as well as provincial borders. However, the full impact of colonial boundaries is not documented, as there have not been recent studies done on interprovincial mobility or mobility from/between communities near provincial borders. In a way, contemporary borders are a creation of colonialism and reflect a western worldview. Pre contact, six main First Nation groups were scattered throughout North America and are categories were created by settlers according to geographical zones and language families (Dickason & Calder, 2006; Government of Canada, 2017). While there were borders and boundaries, there was no single entity governing the land. Each First Nation group had their own governing system. Post contact, the provincial boundaries were initially created with the unification of select eastern provinces in 1867 in which the Dominion of Canada became a nation under the British Crown. Following this, between 1870 to 1905 what is now the prairie provinces joined the Dominion of Canada. With this and the creation of the numbered treaties in western Canada, borders were formalized, and First Nations were restricted to specific areas of land. Thus, borders have major implications for First Nations historically and in a contemporary context. Reserves, treaty territories, provincial boundaries, and federal jurisdictions all act as “borders”. Provincial borders are especially important to understand because of the complexity of the Canadian Health care system (Waldram et al., 2006). First Nations registered under the Indian Act are within the Federal health care system (Government of Canada, 2011). However, diseases such as TB are managed provincially in which patients crossing provincial borders can have major implications for treatment, delivery, and programming (Pan-Canadian Public Health Network, 2013). Thus, understanding inter-jurisdictional mobility is essential.

In one of the few studies to discuss interprovincial mobility, Amorevieta-Gentil et al. (2016) described it as rare, however they did not specifically discuss border communities and the impact of treaty boundaries and reserves on mobility. It may be that interprovincial mobility

occurs more frequently between communities in close proximity to a border, or within treaty areas where communities may have traditional or kinship connections. In many cases the latter cross over provincial boundaries. For instance, every treaty area in Saskatchewan spans either the Manitoba or Alberta border. The partnering communities of study for this research are located near the northern SK and AB provincial borders which are a part of both Treaty Ten and Eight territory and may have implications for patterns of mobility in and out of communities. In terms of access to health care inter-provincial and intra-provincial mobility (i.e mobility within the province) of First Nations may be critical, due to jurisdictional issues. Further research in this area is needed.

2.3.2 Role of Mobility in Health and Healthcare

In order to understand the impact of mobility on TB, it is important to understand the healthcare system and its complex jurisdictions. In Canada TB is managed by provincial or territorial departments (Pan-Canadian Public Health Network, 2013). However, First Nations health on reserve fall under federal jurisdictions. Thus, there are many layers in managing TB in Canada. Under the Canadian *Constitution Act* of 1867 the provincial and territorial governments are responsible for delivery of healthcare services. Through the Canada Health Transfer, the federal government supports the provincial and territorial governments (Government of Canada, 2011). First Nations living on-reserve receive direct federal support through First Nations and Inuit Health Branch (FNIHB) for health through primary care and emergency services. Within SK, Northern Inter-Tribal Health Agency (NITHA) acts as a transfer organization under FNIHB to coordinate and provide care for all northern First Nation communities (Figure 2.2). NITHA is comprised of Prince Albert Grand Council, Meadow Lake Tribal Council, Peter Ballantyle Cree Nation, and Lac La Ronge Indian Band (*The Partnership*, 2020). AB does not have a transfer organization and thus First Nations on reserve are serviced by FNIHB. Mobility between provinces and communities and management of health is complex because of federal and provincial jurisdictions. If a patient is travelling from on-reserve (federal jurisdiction) to off-reserve (provincial jurisdiction) these jurisdictions may impact their access to healthcare. Geographic context of health delivery and the potential relationship between TB and mobility is further discussed in chapter 6 in order to explore the second and third research objectives of this study.

The impact of mobility on access to health care does not appear to be consistent. In studies of intraurban Indigenous migration and health care utilization Snyder and Wilson (2012) found that in Winnipeg every additional move of residence increased the likelihood of the use of a physician, however the opposite was true for Toronto. The increase in physician use may be place-specific, however the exact reasons for the increase in the likelihood of using a physician were not further explored in this study (Snyder & Wilson, 2012). In some studies of Indigenous people, it has been found that frequent travel could be an obstacle to obtaining health care and could lead to interruption in TB therapy (Cumming et al. 1998; Rhoades et al. 2005). Mobility is a complex phenomenon that may affect the utilization of healthcare and transmission of disease. For the purposes of this literature review I focus on the impact of cross-jurisdictional mobility on infectious disease in general due to a dearth of studies on the impact of mobility on TB in Canada. Health risks and implications of mobility can be beneficial, neutral, or detrimental to the spread of infectious disease. The risk factors associated with mobility may depend on the individual and other environmental factors (Macpherson and Gushulak 2001).

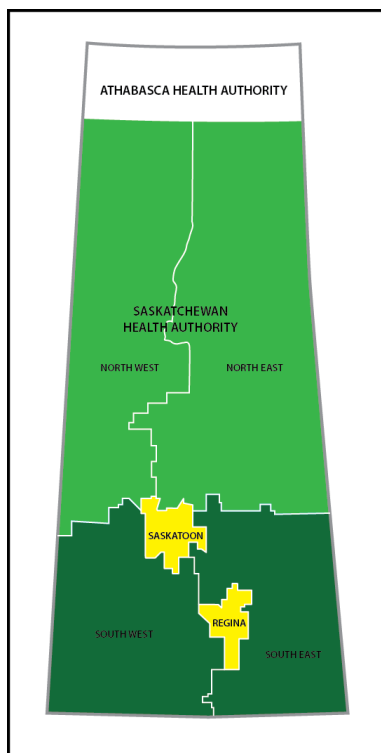


Figure 2.2: Health Network map of Saskatchewan Health Authority based on map created by the Public Health Observatory August 2019

In regard to transmission of infectious diseases an example of negative or detrimental transmission could apply if a TB patient moves from a reserve to an urban center and misses treatment. In a study focused on non-Indigenous persons in California, researchers found that patients who moved during TB treatment were six times more likely to default on treatments than patients who did not move. Defaulting on treatment has a direct correlation to moving, however this study did not explore the specific reasons for defaulting. The rate of default was not affected by whether the treatment was Directly Observed Therapy (DOT)⁶ or self-administered therapy (Cummings et al., 1998). Failing to complete treatment due to mobility can lead to relapse of disease, transmission of active TB, and, possibly, drug resistant strains of TB. In the context of the current study it may be that if First Nations patients are moving across provincial borders from Saskatchewan to Alberta the inter-jurisdictional supports available may not be adequate. Another complication caused by mobility may be that a person may be unaware of their active TB status as they travel as a result the disease may go undiagnosed and/or lead to inadvertent transmission in the new destination. In a study of Indigenous patients with TB and their experiences with health Abonyi et al. (2017) found that although the participants had TB symptoms, the symptoms experienced were not that much different from their usual health status. People may be mobile during a period when they may be infectious but are unaware that their symptoms may indicate TB (Abonyi et al., 2017). However, a beneficial factor of mobility could be having greater access to health care facilities especially in the case of moving from an isolated rural reserve to an urban center. In Canada, TB rates may be magnified in high-prevalence areas due to increased mobility between reserves and urban cities (FitzGerald et al. 2000). With the existence of reserves in rural areas and lack of available resources, there is a need for more research on the impact of mobility on transmission and prevalence of infectious diseases.

2.4 RESEARCH GAP

TB rates among First Nations people remain disproportionately higher in comparison to Canadian-born non-Indigenous people (Canadian Lung Association et al. 2014). The persistence

⁶ Directly observed therapy (DOT) is the process of a health worker watching the patient swallow each medication for the treatment of active TB. This is the national standard of care in Canada (Canadian Lung Association et al., 2014; Iseman, 2000).

of TB at high rates in some, but not all, First Nation communities indicates that there is a need to focus on determinants of health and other factors in order to explain these patterns. Mobility may be one such contributing factor to the continued TB prevalence among First Nation communities. Several studies have highlighted the need for more research on the relationship between mobility and TB transmission; however, little research is available thus far (Eisenbeis et al., 2016; Long et al., 2013; Mayan et al., 2017). The few studies available on mobility and healthcare focus on urbanization of Indigenous people of Canada. However, due to increased urbanization, short-term mobility may be increased between jurisdictions, i.e. visiting reserves. With the focus on urbanization and migration, there is a lack of research on on-reserve First Nations population mobility. Additionally, the patterns of mobility (both spatial and temporal) as well as the factors serving to motivate these movements, may be different for communities located within a single treaty area and in close proximity to provincial borders. *Pathways Project* is focussing on high incidence border communities between AB and SK. Within the two border communities in SK, the overall rate of TB between 2007 to 2017 was 405/100,000 (Long, 2018). At present the full set of factors to explain these high rates in the communities (and the persistence of the disease) have yet to be identified. One possibility, and the basis for this thesis, is that interprovincial mobility may be contributing to this pattern. As noted above, these inter-jurisdictional mobility patterns have not yet received attention in the literature, especially in Canada.

Furthermore, there is a need for more research on the impact of different types of mobility on the transmission and prevalence of TB. TB treatments in many communities includes DOT, however DOT is not a federal requirement and communities can choose to enforce it (Canada and Health Canada, 2012). Problems may potentially occur when First Nations patients are mobile between jurisdictions, and they may fall out of the province-based TB care programs. This could be especially true for communities located near the border of Alberta and Saskatchewan. If First Nations patients on-reserve under federal jurisdiction are moving from SK to AB temporarily, their change of location may affect their access to treatment and TB transmission.

CHAPTER 3:METHODS

The previous chapter reviewed the relevant literature and provided a foundation for understanding the nature and history of TB among First Nations of Canada. Building on this, the present chapter outlines the methods utilized in the study in order to better understand the relationship between mobility and TB. Before explaining the methods and design used in the study, I outline the steps taken for collaboration with the communities and partners involved. Then I explain the research design, in which I justify the use of a qualitative approach in order to understand inter-jurisdictional mobility and TB care programming. Qualitative research is defined as “the development of concepts which help us to understand social phenomena in natural (rather than experimental) setting, giving due emphasis to the meanings, experiences, and views of all the participants” (Pope & Mays, 1995). Then I explain the rationale for using an instrumental case study approach. In the third section, I explain data collection, and sampling procedure used during the study. This then leads into a description of methods of data analysis and limitations of the study.

3.1 RESEARCH COLLABORATION

This project was conducted with the support of CW which served as the setting for the research. Without their generous assistance this study would not have been possible. My initial partnership with the community was established through a CIHR-funded project, *Implementing the “Patient’s Charter of Tuberculosis Care” in high incidence Indigenous communities and across jurisdictional borders* also known as Pathways Project. Pathways Project was in its 2nd component during the study period for this research in which an overall TB advisory committee was created with representatives from the four partner communities (CW (SK), SK community 1, and two partnering communities from AB) which oversees and works with the academic partners. The current research was carried out under the umbrella of the Pathways Project and received oversight and guidance from our community partners as described previously in chapter 1 page 8. I utilized a community based participatory research (CBPR) approach for this research. CBPR refers to an overall approach to research in which the community and other non-academic partners are involved throughout the research process. The research followed the nine principles outlined in “Methods in Community-Based Participatory Research for Health” throughout the

creation, implementation, analysis and dissemination of research (Israel, 2013). I worked with and received guidance from a community TB research committee comprised of healthcare workers from CW and SK community 1 as well as local community leaders, this committee is distinct from the previously mentioned TB advisory committee, it operates only in CW and SK community 1. The initial research concept and design were presented to the full TB advisory committee on October 5th, 2018 and changes to the direction of the research were made based on their advice. Once the research process was fully defined, my supervisor, Dr. Hackett, and I applied for and received approval from the University of Saskatchewan Research Ethics Board to proceed with the project. Upon completion of data collection, a summary of results from interviews and document review were distributed to the TB research committee. TB continues to carry a stigma that First Nations may not wish to have associated with their community. TB is a legacy of colonization, studies have found that historical treatment of TB continues to carry fear and stigma of TB in the 21st century (Komarnisky et al., 2016). There is no single practice guiding how Indigenous communities are referred to in health studies. As a consequence, I consulted with the TB research committee to establish a protocol for naming CW in the thesis and will continue to consult with the committee for future publications. Although there was a lack of response collectively, permission was obtained from a member of the community TB research committee, and I was informed by them that the committee has given permission orally. Based on the research objectives and questions presented in Chapter 1, this study has two major components: (1) an exploration of mobility patterns and motivations among CW members; and (2) an analysis of the current state of TB policies and treatment in AB and SK. These components are further explained later in this chapter.

3.1.1 Study Setting

CW is a First Nation community located in northwestern SK adjacent to the provincial border of AB. The geographical location of CW is approximately 57° north latitude and 109° west longitude. It encompasses a land area of 7,200 acres and is located approximately 6 km North of the Métis village of La Loche. Due to the close proximity to La Loche, the relationship between the two communities is an important factor to consider in this study. Nearby border communities across the provincial border in Alberta include the hamlet of Janvier, located 189 km from CW, and Fort McMurray, a city defined as an urban service area and having a diverse

population, located 204 km from CW. The degree of connection and the nature of travel between CW and these three communities is a critical question to be examined in this thesis.

CW was formerly known as the Portage La Loche Band that included Indian Reserves 221, 222, and 223. Indian Reserve 222 is now classified as the village of Clearwater River by Government of Canada. As of 2013, Clearwater River has 1,875 members; 804 live on-reserve and the rest of the members live off-reserve (Meadow Lake Tribal Council, 2020). In 1899 the community signed Treaty 8; CW is a Dene First Nations Band⁷ governed by one chief and five First Nations councillors in CW. The main languages spoken in CW are Dene and English. 675 people speak the Northern Athabaskan language Dene and according to Statistics Canada the entire population speaks English (Meadow Lake Tribal Council, 2020).

3.2 RESEARCH DESIGN

This research focuses on understanding inter-provincial and inter-jurisdictional patterns of mobility of First Nation community members and their potential impact on TB by way of limitations in TB policy and care and prevention programs. In order to better understand this as a broader phenomenon, I utilized a case study approach to explore the movements of community members and evaluate how these may impact TB care and prevention programming, and transmission. A case study is defined as research that involves the study of a case or cases within a setting (Creswell & Poth, 2018). There are several types of case study approaches, this research is an instrumental case study. An instrumental case study is a type of case study in which the case is secondary to the phenomenon of focus and thick description is obtained about a group (Mills et al., 2010). Thick description is exploring and gaining in-depth perspective into a phenomenon through the use of multiple methods (R. Taylor & Thomas-Gregory, 2015). For this research the phenomenon of focus is mobility and its possible impact on TB care and prevention.

The case study takes place in CW, a First Nation community in Saskatchewan located close to the provincial border of Alberta. This location is crucial, as it is surmised that cross-boundary (and thus interjurisdictional) mobility can have an impact on TB that is distinct from

⁷ According to the Indian Act, “Band” is defined as a body of Indians for whose use and benefit lands have been set apart. (1985)

other forms of mobility, and that movements across borders will likely be more frequent among members of communities that are in close proximity to a border. Different methods and approaches were used for each of the two components of this study. For the mobility piece I conducted in-depth semi-structured interviews and phone interviews with community members. For the policy piece I carried out a review of key TB documents including provincial, national, international, and documents pertaining to Indigenous groups in Canada. The two phases allowed me to gain a deeper understanding about inter-provincial mobility between SK and AB and its possible impacts on TB. My discussion of the study results and its implications are found in later chapters.

3.2.1 Justification for Qualitative Approach

This study is exploratory in nature and seeks to understand phenomena that are not easily quantified. While mobility patterns, timing and frequency may be measured, the specific motivations and their effect on TB care and prevention policies are harder to quantify. Therefore, a qualitative approach allows me to better understand the patterns behind mobility, and to address potential effects on TB control. At this stage a qualitative approach offers several important benefits over quantitative methods, including the fact that it lends itself to rich descriptive analysis, provides flexibility in terms of collecting and interpreting complex data, and makes theory-building (in the absence of prior research) possible (Al-Busaidi, 2008; Black, 1994).

3.2.2 Rationale for Instrumental Case Study

The goal of this research is to understand a broader phenomenon, mobility and its impact on TB and health, and to provide guidance as to how policy and procedures in Canada might be adjusted to help address the persistence of disease among high-incidence communities. Given this, an instrumental case study is appropriate for this research. An instrumental case study enables a researcher to explore a specific example or ‘case,’ such as an occupation, community, or person, in order to gain insights into a larger phenomenon. Instrumental case studies allow for generalizability while still focusing on the experience of the study participants through thick description. Defining the boundaries of a case ensures that a study will remain within a reasonable scope, and boundaries indicate what will and will not be studied for the research

(Baxter & Jack, 2008). There are two elements to the boundaries of this case, (1) a single SK First Nation community in close proximity to the SK and AB provincial border, and (2) First Nations residing in and living on reserve in said community.

3.3 DATA COLLECTION

Data were collected in two phases corresponding to the two research components: (1) motivations and patterns of mobility, and (2) review of TB care and prevention programming through a document review and interviews with healthcare workers. In total I interviewed 19 participants for the two interview components. 11 of the total interviews were with healthcare workers and 11 were with community participants. Three of the 19 participants were both healthcare worker and community participants. Although these two components are quite different in approach and the type of data that was obtained, rather than following a linear timeline I pursued both components simultaneously. This enabled me to adjust interview questions throughout the research and review and validate my findings by comparing findings from both components.

Component 1: Motivations and patterns of mobility

I conducted a total of 11 semi-structured in-depth interviews with community participants during five visits to CW over the period of May 2019 to August 2019. These interviews took place within an overall research approach based on Community-Based Participatory Research, or CBPR. CBPR refers to an overall approach to research in which the community and other non-academic partners are involved throughout the research process (Israel, 2013). In this case the main partnership was with the TB committee in SK community 1 and CW which consisted solely of community members. Thus, before beginning the data collection process initial idea and methods were presented on May 14th, 2018 at the annual Pathways meeting in Edmonton. This meeting consisted of project members, community partners, including community partners from CW and SK community 1. Following this, on October 5th, 2018 research design was presented to community partners from CW, SK community 1, and the two AB partner communities. During this meeting, feedback was received from how data collection can be modified, this was an essential turning point that shaped the research design immensely.

The first unofficial visit to CW took place on December 4th, 2018 which, although not a part of the data collection process, was an essential visit as it enabled me to begin the process of establishing our collaboration. During this visit, I met the main health workers in La Loche and CW as a part of the community-run outreach event in La Loche. The outreach event was aimed towards a specific demographic in the community that is impacted by low socioeconomic status, substance use, and other difficulties. The event included front line workers from different areas such as HIV/AIDS, flu virus, nutrition, and TB and provided a free hot meal for participants. This event allowed me to get to know community members by volunteering as a food server and providing attendees with care packages. During this visit, the TB research committee gathered allowing me to meet the main community members that acted as guides for this research. Following this, I visited the community an additional five times. During the first official visit, I volunteered in the CW school, did radio interviews, and visited with community members. These activities enabled me to get to know the community better and allowed for community members to get to know me. The next four visits consisted of interviews, volunteering, and participating in Treaty Days. A total of 11 community interviews were carried out and all interview data was anonymized in order to ensure privacy and safety of the interviewees. All community participants are referred to by as a “community member #” or “teacher” in the thesis. All confidential participant information collected is stored on a drive and reviewed only by me.

The semi structured interviews with the community members were in-depth and allowed the participants to share their stories and motivations behind mobility. Thus, I employed a smaller number of broader questions in order to encourage the participants to share what they believed was important (Appendix A). I conducted the interviews in locations chosen by participants. Settings ranged from the CW school, to the local health centre, to participants’ homes. I believe allowing the participants to choose the location helped deformatize the process and made them feel more comfortable with being interviewed. The interviews used open-ended questions that were devised following the first pass read of the document analysis and the literature review (Appendix A). This structure of the interviews led to discussion; one interview was 10 minutes while others ranged from 20 to 45 minutes in addition to the time taken for the consent process. I found that many of the participants shared stories of travels, and these stories unfolded as they became more and more comfortable with sharing. The in-depth interviews gave the participants more control over the process and helped mitigate power imbalances. All

interviews were recorded and transcribed verbatim and analyzed. Written consent was obtained from each participant prior to recording, and some opted for no audio recording. All were comfortable with note-taking through the interviews. The goal of this component was to understand mobility patterns and motivations. As a gesture of appreciation, a small honorarium was given to each participant.

Component 2: TB policy, and care and prevention programming

Currently there is a lack of systematic evaluation research of TB policies and care in Canada. In order to understand the existing gaps, I employed a documentary analysis approach. Document analysis is defined as a systematic procedure for reviewing documents and requires that the data be analyzed in order to gain further understanding of the research topic (Corbin & Strauss, 2008). This technique is used to investigate and identify limitations of physical and virtual sources such as written documents. Although First Nations health lies within the federal domain, TB care, prevention and policies are provincially governed and implemented, and, as such, there is no standardized national TB program. Nevertheless, suggested guidelines at a federal level exist. To understand the impact of inter-provincial mobility it is especially important to evaluate current provincial TB policies and care programs. Items selected for the document review consisted of past and current policies and guidelines at the provincial (AB and SK), national and global scales. Provincial TB Strategy and Training documents were obtained from the SK government website under its Saskatchewan Health Initiatives (https://www.saskatoonhealthregion.ca/locations_services/Services/TB-Prevention) and from the Alberta website (<https://www.alberta.ca/open-government-program.aspx>) from its Open Government Program (Table 3.1). National and provincial policies pertaining to Indigenous populations documents were obtained from the Government of Canada websites and portals. It is important to note that there may be other policy documents in place that were unavailable to the researcher at the time of this document review. In an attempt to access documents, I contacted TB control SK, however due to the current restructuring of the TB strategy only the online documents are available. The findings from the document review were then compared to the reality of care by way of interviews with healthcare workers, assisting me to identify any gaps that exist in current policies, specifically regarding inter-jurisdictional mobility. The documents

were analyzed multiple times concurrently with the interviews, which allowed a more in-depth understanding of the reality of TB care and prevention.

Table 3.1: List of documents analyzed for document review

	Documents Selected	Data Analyzed
Saskatchewan	Saskatchewan Provincial TB Strategy 2013-2018 (TB Partnership Working Group, 2013)	<ul style="list-style-type: none"> • Objectives and goals • Current TB care and prevention programming • Inter-jurisdictional policies and programming
	TB Prevention and Control Saskatchewan Clinical Policies and Procedures (Saskatchewan Health Authority, 2018)	<ul style="list-style-type: none"> • Current TB care and prevention programming • Inter-jurisdictional policies and programming
	Saskatchewan TB Program Worker Handbook (TB Partnership Working Group, 2013)	<ul style="list-style-type: none"> • Current TB care and prevention programming
Alberta	Tuberculosis Prevention and Control Guidelines for Alberta (Government of Alberta, 2010)	<ul style="list-style-type: none"> • Objectives and goals • Current TB care and prevention programming • Inter-jurisdictional policies and programming
	Tuberculosis in Alberta Surveillance Report (Government of Alberta et al., 2014)	<ul style="list-style-type: none"> • Healthcare structure and programming
Policies regarding Indigenous Peoples	Indian Act (Indian Act, 1985)	<ul style="list-style-type: none"> • Indigenous lands and treaty status
	TRC Calls to Action (Truth and Reconciliation Commission of Canada, 2015)	<ul style="list-style-type: none"> • Inter-jurisdictional policies
	Health Canada's Strategy Against TB for First Nations On-Reserve (Canada & Health Canada, 2012)	<ul style="list-style-type: none"> • Current TB care and prevention • Mobility and inter-jurisdictional policies and programming • Risk factors and SDOH
National	Canadian Tuberculosis Standards 7 th Edition (Canadian Lung Association et al., 2014)	<ul style="list-style-type: none"> • Current TB care and prevention programming recommendations • Inter-jurisdictional policies and programming • On-reserve and high incident community recommendations

	Canada Health Act (Canada Health Act, 1984)	<ul style="list-style-type: none"> • Inter-jurisdictional policies
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The healthcare worker interviews noted above took place with healthcare and TB workers from CW as well as the three other nearby communities that are part of the *Pathways Project*. This enabled me to obtain a perspective based on both the AB and SK jurisdictions, which was critical in order to consider the impact of cross-boundary movements. These interviews were in-depth and semi-structured, and the initial questions were created from the literature review and the research gaps identified earlier. The questions (Appendix B) focus on current programming, inter-jurisdictional policies, and procedures regarding mobile patients. I interviewed 11 health workers with current or past professional experience relating to the four project communities. Interviews were conducted in person or, for those who were unavailable, over the phone. In addition to clarifying gaps in the current provincial and national TB policy, these interviews helped provide insights into the impact of mobility from a health worker’s perspective. All interviews were recorded with permission and transcribed verbatim.

3.3.2 Sampling Procedure

Snowball sampling technique was used to recruit the community interviewees. Inclusion criteria for community participants were that participants must be 18 or older and also residents of CW or the close research partnering community near CW. Exclusion criteria included children under the age of 18, and participants living outside of CW and SK community 1. Snowball sampling is a non-representative strategy for identifying and recruiting potential study participants based on the recommendations of existing participants, who may determine that others may be interested or “information-rich” (Naderifar et al., 2017). Essentially, a few participants are requested to recruit others from their communities through “word of mouth”. This sampling technique is advantageous due to the potential sensitivity of the subject. By relying on individual recommendations, rather than mass advertisement, it can enable researchers to find participants who may be difficult to identify without assistance. In this case I worked with the community and TB committee to secure the initial interviewees. The target sample for community interviews was an undefined number of First Nation community members from the partner First Nation community. This included one member from SK community 1 and 10 from CW. All community members were over 18 years of age and spoke English.

The sampling for health workers varied by role and community. Purposive sampling was carried out by directly contacting specific health workers involved with TB care and prevention programming and policies within both SK and AB. Inclusion criteria for health worker interviews varied. I focussed on physicians working with TB patients within AB and SK, TB workers from CW and Pathways partnering communities, TB nurses and other health workers involved with TB including healthcare providers from NITHA. Exclusion criteria included healthcare providers not directly involved with TB in communities. Interview questions asked from health workers (Appendix B) were significantly different from the community participant interview questions. The focus of the health worker interviews was on current TB policies, inter-jurisdictional policies and programming, and mobile patients. Some similarities presented between the health worker interviews and community interviews when health workers discussed mobility patterns of patients, or their own mobility experiences. For the three participants that were both health workers and community participants, I conducted the community participant interview first followed by the health worker interview questions. The overlapping participants helped me further understand mobility patterns of other community members and of active TB patients.

3.4 DATA ANALYSIS

The qualitative data from the interviews was transcribed using DSS Player Pro Transcription Module and analyzed using NVivo 12 (QSR International). This qualitative data analysis software was used in coding and thematic analysis of the interview data. The interviews were transcribed verbatim and reread a few times to understand the full meaning of the stories. During the consent process before the interviews, all community participants were asked on the consent form if they wish to review their transcripts. None of the participants wanted to review transcripts. Health worker interviews were transcribed verbatim using the same transcription software.

Once all community interview data was transcribed thematic analysis was done using NVivo by finding connections and identifying existing themes. Creating the themes was an iterative process. The initial codes were created using the background information from the literature review and the objectives of the study. Then through the first few read-throughs of the

transcripts, codes were created based on recurring words and themes. Patterns, locations, and motivations for mobility out of the community emerged throughout the reads. Arguably, for this project the creation of codes was both an inductive and deductive process. It was inductive because there is a lack of theory and research surrounding interprovincial mobility (and its health effects) and initial codes were created from the first read through. However, the existing information on mobility patterns and possible motivations helped create the initial codes. Due to the lack of theory on inter-jurisdictional and inter-provincial mobility the research is more exploratory in nature. At the same time, there is a clear question to be answered and phenomenon to be analyzed. The codes were then categorized to themes from their relationships and linkages.

A similar process was followed for health worker interviews and the document review. The initial codes for the document review were created based on the background literature and research questions. The codes for health worker interviews were created initially based on the background literature. Many of the codes for health worker interviews and the document review were the same and focused on current TB programming and policy, and mobility policies. After the first read through of the health worker interviews and the document review, codes were created based on recurring themes. The purpose of the document review was to understand current TB care and prevention programming, and the role of mobility and gaps in policy. Keeping this in mind, the initial codes included, among others, treatment, policy, mobility. These were used to answer the primary research questions. The health worker interview codes were created based on initial literature review findings, as well as the codes and themes from the document review, as a means of understanding the reality of frontline TB care and prevention. Based on the codes and themes, I utilised ArcMap 10.6 to create provincial maps to depict patterns of mobility. ArcMap is a software used to display datasets in map layouts and represents geographic information as a collection of layers (*What Is ArcMap?*, 2016). I used route analysis through the network analysis tool in ArcMap to create a route map for major destinations out of CW. Based on descriptions from community participants, I manually drew in the winter road that connects CW and Fort McMurray in the winter. All maps and diagrams were created by me, unless otherwise stated.

Rigor is the strength of the research design, its appropriateness to answer questions, and the trustworthiness of the qualitative analysis (Cypress, 2017; Maher et al., 2018). This is

especially important in qualitative research because of the potential for subjectivity. Forero et al. (2018) discusses four main criteria for establishing trustworthiness described by Lincoln and Guba: creditability, dependability, confirmability, and transferability. For each criterion, a strategy for analysis was created (Forero et al., 2018). Creditability is establishing confidence that results are true, credible, and believable from the participant's perspective. I worked to establish credibility by engaging with the community, presenting the interview guides to Pathways Project community and research partners, as well as the TB advisory committee. Once all interviews were conducted, participants were given the choice to review their transcripts, although most opted for not reviewing the transcripts. As an alternative, I provided research finding summaries to the TB research committee and presented to the Pathways project partners and TB advisory committee. Dependability is established by the rich description provided about the research methods followed. Confirmability can be established through reflexivity and triangulation. Reflexivity was ensured by a detailed journal I kept throughout my research. Triangulation is the use of multiple research methods to increase credibility, this was done by the use of multiple methods to conduct this research (Bowen, 2009). And lastly, transferability is the extent to which the results can be generalized. A strategy to achieve transferability is data saturation (Cypress, 2017).

Data saturation is reached when no new information or coding emerges, and is a signal for the researcher that data collection can end (Matthes et al., 2017). Saunders et al (2018) discusses four models of data saturation, inductive thematic saturation looks for the 'non-emergence' of new codes or themes. I would argue that inductive thematic saturation was used for the mobility aspect of this study in which no new themes emerged in the community interviews as such the motivations and destinations of mobility became repeated throughout the interviews. In component 2, inductive thematic saturation was reached when I created a full picture of the reality of TB care and programming in comparison to the policies on paper.

3.5 LIMITATIONS

There were several limitations to this study. Many, although not all, of the community members interviewed were professionals in the community, and their patterns of travel may not be reflective of the CW population as a whole. Moreover, between SK community 1 and CW,

there is also a significant transient population that may at times be homeless and who may face significant personal challenges in terms of the DOH. These people were not interviewed, and so their experiences are not fully captured in the results. These individuals may be especially vulnerable to falling through the cracks in the system, and, perhaps, to acquiring active disease. Further study would be necessary in order to fill this gap, and such a project would require the expenditure of substantial time and resources towards developing a partnership with this community.

Secondly, gender and age of mobile populations were not considered as distinct analytical categories due to the relatively small scope and timeline of this project. Mobility almost certainly is gendered, especially when considering travelling for work purposes for mining and oil camps, however the same may be true for those travelling for family obligations and commerce. Similarly, the nature of travel, in terms of motivations and spatial and seasonal patterns, may change over the life course. For this study I did not have a sufficient participant size that would enable me to consider these differences.

Additionally, CW and SK community 1 have TB projects and programs within them, some of them offered in collaboration with our overarching Pathways group. This is particularly the case for our four partner communities in SK and AB. These resources are not available in all communities in the region, and thus conditions in CW are not likely to be fully reflected in some respects elsewhere. This may mean that certain findings of the study are not directly transferrable to other communities.

Finally, for the second part of this study limitations in access to data may be of some significance. For the document review, all documents accessed were open source, available on the Internet. Although I sought to gain access to all relevant official materials concerning TB control in each of the jurisdictions, and made multiple inquiries to the appropriate authorities, no additional material was forthcoming. It remains possible that additional policy and healthcare guidelines may exist but are limited in availability to health personnel. For future studies, these limitations need to be considered.

CHAPTER 4:MOBILITY OUT OF A SK BORDER COMMUNITY

This chapter presents the findings from the interviews with community members about mobility. Mobility is a complex word with many different meanings. As noted earlier, for the purposes of this research mobility is defined as the temporary movement out of or into a partner community. Mobility is further broken down by its duration of short term or long term. Short term includes travelling out of the community of residence for a week or less, while long term mobility is travelling out of the community of residence for more than a week (up to a period of months but less than one year). Migration is mobility out of community with a change in residence from their home community. Keeping these definitions in mind, I explore and analyze the various mobility patterns and motivations I found through the community interviews. The first part of this chapter describes what role land and home play in peoples' lives and its relationship to mobility. The second part considers mobility out of CW, a SK First Nation reserve and the second part is further divided into four subsections. The first explores the major destinations out of the community, this includes both inter-community and inter-provincial mobility. The second outlines the major motivations for these movements. The last subsection explores the temporal patterns, modes and temporal lengths of mobility out of the community.

4.1 ROLE OF LAND AND HOME

"Home" has many meanings that may be determined by an individual's worldviews which in turn is largely shaped by their culture. Although it varies between groups or societies, people's attachment to homeland is universal (Tuan, 2011). Indigenous peoples worldwide in particular have a deep connection to the earth, and surrounding land. There was an emerging pattern of "home" being the land, culture, family, and reserve. In Indigenous worldviews, home is not just one location or place, but it is the land, or mother earth (Wilson, 2003). The human geographer Yi Fu Tuan talks of mobile people such as hunter gatherers, and among these people the sense of home is very important. Attachment and rootedness may be even stronger. An example he uses is the Native Americans of the American Plains who are highly mobile and view earth as mother, as a provider of water and growth (Tuan, 2011). This same sentiment was common among the Dene peoples in CW. CW, other reserves, La Loche, "The North", and "God's country" were often given in answer when asked what home means to them.

Home, home means to me the land the people, the community, that's my answer.... Right here in CW and La Loche both I consider home, I've grown up here all my life so I consider it all home, this land. [Community member 1]

There is a strong sense of home in its connection to the community and the land. This connection to the land and sense of responsibility is reflective of Dene history and culture. The land and place are connected to First Nations health, not just as physical environments or settings, but they also derive meaning from physical, symbolic, spiritual, and social aspects of First Nations cultures (Wilson, 2003). The reserve itself and the surrounding land and communities nearby were also identified as being home. Although reserves were originally created as a way of assimilating and “civilizing” First Nations people, in present day reserves also represent a “refuge from non-Aboriginal society, a place where the bonds of community are strong and where Aboriginal culture and identity can be learned and reinforced” (Royal Commission, 1996). CW reserve is located in close proximity to the neighboring community of La Loche and the two communities are closely related. The reserve is home to not just the members of CW but also to a more transient population that visits from around the community and the province. However, the latter population, including the homeless or mobile population of La Loche, did not participate in the interviews which were limited to residents of CW and a nearby partnering research community (perhaps in part due to the limitations of the snowball sampling technique). La Loche and CW together are both considered home for many individuals, and this may play a part in the complexity of healthcare due to CW being federal jurisdiction and La Loche being under provincial jurisdiction. La Loche is off-reserve and a provincial community although members of both communities are often very closely related. While CW is a reserve, participants also identified the idea of “reserve” in general as home as well. “Reserve, family, community, traditions” [Community member 2] and “...then moving to Black Point (Northern hamlet in SK) and reserve but all my life I call reserve my home.” [Community member 3]. Reserve was considered home where there is access to culture, language, food and other traditions. It may be a place of safety as well as freedom whereas a city was not considered home, even for those individuals who were raised in urban settings.

Home to me is being in a community that has a close knit kind of feeling, you know when I go to the city it's not home even if my daughter is living there it doesn't feel like home. But here I don't know maybe it's a cultural thing
[Community member 4]

The lack of family, culture, and traditions in cities was a reason that cities and urban settings are not considered home. In many interviews, home was also defined by culture and tradition. There is a strong sense of belonging and cultural identity in the community.

As a group, participants equated home with family and kinship networks. It is important to note that the meaning of “family” differs between westernized and Indigenous worldviews. Family from a western perspective is bound to immediate and extended, while in Indigenous worldviews family is based on broader relationships, culture, and is fluid (Tam et al., 2017). Specifically for First Nations people, family is the heart of the people (National Collaborating Centre for Aboriginal Health, 2015). Through the interviews, grandchildren and great grandchildren were an important aspect of home. People are closely related across communities and the relationships are an important aspect of how participants defined home. As one community member eloquently put,

Home to me is where all my relatives are, and this is home for me, home is where I'm able to come home and freely speak my language and where I can have access, when I'm home I have access to my traditional food and I have access to my language and my culture, where I can practice my culture, and it's CW this is my home [Community member 5]

Land, culture, home, family, and reserve are all interconnected themes, none separate from the others and all these in combination make up “home”. The idea of home and land also plays a major role in motivations for mobility out of and into the community. Many of the participants emphasized that although they travel out of the community frequently, CW is their home. The role of mobility is further examined in the next section, along with what role land and home plays in mobility.

4.2 MOBILITY OUT OF A SASKATCHEWAN BORDER COMMUNITY

When asked about the importance of mobility respondents identified travel as being a key component of the lifestyle of community members. Generally speaking, travel fulfilled several needs, among them entertainment and the need to obtain necessities that are not available in the community. This section explores the specific role mobility plays in the lives of the members of this border community. The first part identifies the main destinations of mobility out of the community. Although mobility forms a part of individuals' long-term plans, it also commonly plays out as part of their daily life. For the community members interviewed for this study, some of the many destinations identified are part of their activity space. For the people of CW, certain destinations are a part of an individual's daily activities, while others are frequent but not daily destinations. The connection between the social and physical environments is an important part of understanding activity space, thus the second part explores the motivations for mobility. Common patterns for both destinations and motivations emerged in the analysis. The last part explores the temporal patterns and modes of movement out of the community.

4.2.1 Destinations out of Community

The pattern of travel out of CW is diverse and complex, as community members targeted numerous other near and more distant communities as destinations. The existence of multiple jurisdictions for destinations makes travel patterns even more complex. In turn, cross-jurisdictional travel can have significant repercussions for healthcare utilization given the fractured healthcare landscape, this is discussed further in chapter 5. During the interviews, participants identified multiple common destinations of mobility out of CW (Figure 4.1). In Saskatchewan, the destinations included cities and other smaller communities and reserves. CW is closely related to its neighboring community of La Loche both geographically and through social/family relationships. La Loche is located 6.5 km south of CW (Figure 4.1) and is connected by a paved road and a gravel road and La Loche is the closest neighbouring community. "I noticed that La Loche definitely travels throughout the year." [Community member 6] Mobility between these two communities is a part of everyday life and the two function almost as a single community for community members. Often people refer to La Loche as "going into town" or "going to L.A." La Loche is thus part of the activity space of CW

residents. La Loche has a full health centre with extended treatment capacity, and access to groceries and schools. It is also home to family for many of the CW residents. From a jurisdictional standpoint the two are quite different. CW is considered on-reserve and therefore under federal authority while La Loche is off-reserve and under provincial authority for healthcare. Therefore, although they are only 6.5 km apart and they constitute a single activity space, they exist in two different health jurisdictions.

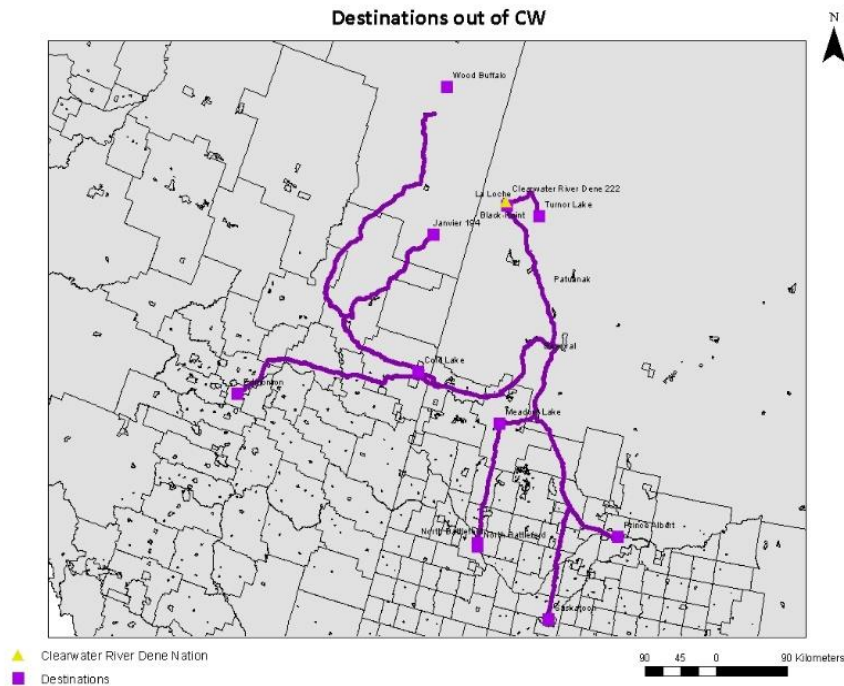


Figure 4.1: Map showing general driving routes to destinations out of CW

Saskatoon is the second major destination out of CW next to La Loche, by frequency of mention. Every individual interviewed had Saskatoon as a destination out of CW for various reasons. Medical travel to Saskatoon is the most common. Although La Loche has a full health centre and CW has a health centre with some capabilities, many medical appointments take place in different cities around Saskatchewan. In Saskatoon, travellers attended dental, optometrist, specialist, and hospital visits. The path to Saskatoon is 650 km which, according to community members, is a six-and-a-half-hour drive. The frequency of travel to Saskatoon ranges from once every couple of months to multiple times in one month depending on motivations and the individual. Saskatoon also has more affordable groceries than found either locally or in nearby communities, and by virtue of its greater size more varied shopping is available. Trips are

planned to accommodate both shopping and medical consultation in a single visit. Saskatoon is also a destination for work, family, and friends. The specific motivations are explored in detail in the next section of this chapter. As noted, mobility within Saskatchewan crosses jurisdictions from on-reserve (CW) to off-reserve (most other destinations) which may have implications for health jurisdictions.

CW is located only a 73.3 km drive from the AB border, which respondents estimated to require about an hour of travel time by car. Garson Lake is a small community located directly adjacent to the border between AB and SK. According to community members, Garson Lake lies in both Alberta and Saskatchewan. Highway 956 to Alberta allows seasonal access to this community. However, as a winter road this highway is only open for a short period of time, generally between December and March depending on winter conditions, and is closed during summers (Markusoff, 2016; RD Laloche, 2012). While open, this highway allows close access to major destinations in Alberta (Figure 4.2). The most common destinations for travel from CW are Janvier, Cold Lake, Fort McMurray, and Edmonton. Cold Lake and Janvier are mostly accessed for social connections such as friends and family. Fort McMurray is the major travel destination in the winter from CW in Alberta. This is because of the winter road that cuts travel

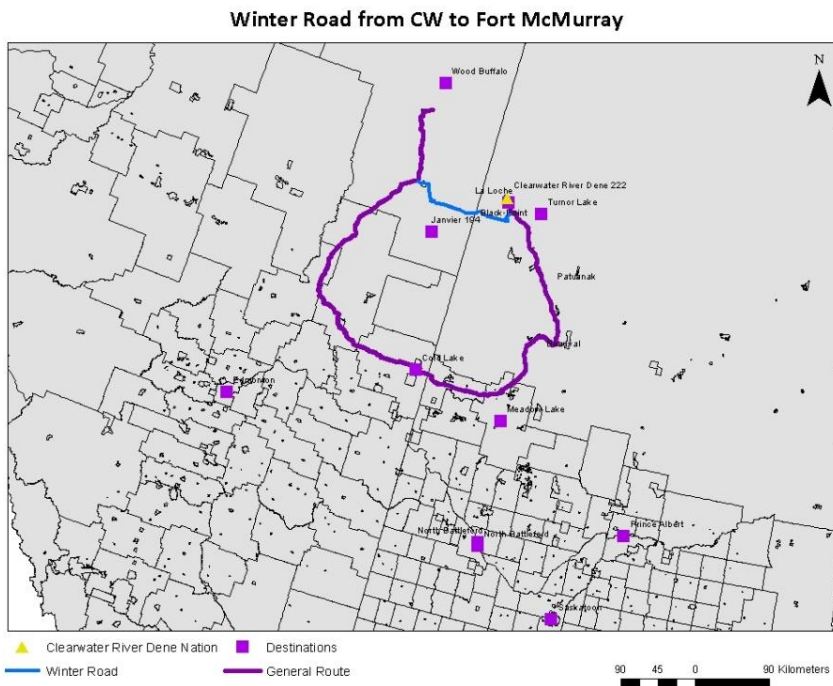


Figure 4.2: Seasonal Road map from CW to Fort McMurray

distance on existing roads from 938 km in the summer to 231km in the winter. Community members described the trip as only 2 hours in the winter compared to the 9 hours in summer.

However, winter roads require slower driving and lack cellphone services, gas stations, and road patrol (La Loche Winter Trail, 2020). Fort McMurray, a city of 66573 people, has more entertainment, shopping, and more affordable pricing for essential groceries than all other destinations excluding Edmonton and Saskatoon, especially in comparison to La Loche. Although La Loche is a closer destination, Fort McMurray has many pull factors for CW community members in the winter. The motivations for mobility out of the community within Saskatchewan and Alberta are similar. The following next section discusses these motivations in greater detail.

4.2.2 Motivations for Mobility

The interviewees identified several different motivations for travel out of CW. Major categories included education, entertainment, family, medical, pilgrimage, shopping, traditions, work, and “cabin fever.” The latter is a colloquial term that was often used by community participants referring to the need to leave the community due to feelings of restlessness, boredom, and needing to break the routine (Rosenblatt et al., 1984). As discussed in chapter 2, mobility and migration researchers identify push and pull factors as categories of motivations for people to engage in a change in residence. For the purposes of this thesis I use push and pull factors as reasons for mobility that is not contingent upon a change of residence (Figure 4.3) (Clatworthy & Norris, 2007).

In general, push factors are negative internal characteristics of a place tending to push people to leave a location, while pull factors are positive attributes drawing individuals to an external settlement. A major push factor out of CW is the lack of resources and activities available in the community. The lack of resources includes necessities such as affordable groceries, and access to specific healthcare programming such as medical specialists, dental practitioners, and optometrists. Lower socio-economic status may exacerbate these factors, as some leave to seek education, housing, and employment opportunities. However, working against these pull and push factors are stick factors (Figure 4.3), the strong connections to culture, land and family that exist in the community. These may work to make those trips only

temporary rather than permanent. Pull factors or benefits of destinations identified include better healthcare, traditions, employment opportunities, entertainment, and affordable groceries and shopping opportunities. This section explores major motivations or the push-pull factors of mobility out of CW.

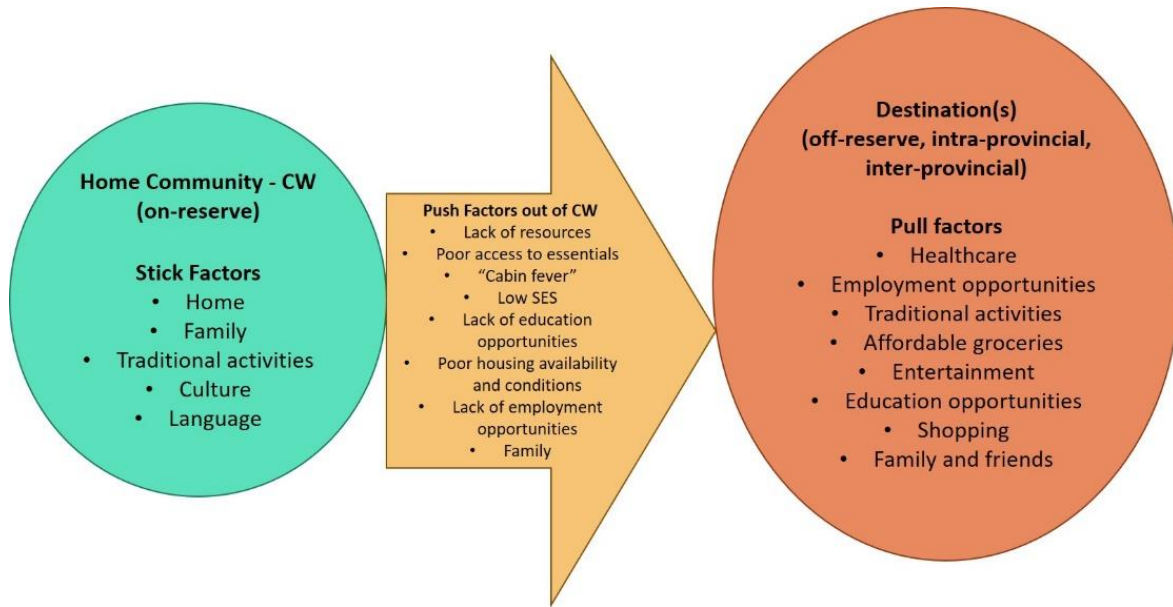


Figure 4.3: Diagram describing the push/pull and stick factors for mobility out of CW

Interviewees stated that groceries and supplies available near and in the community are expensive, I noticed that each of the stores had higher prices for the few available fresh groceries compared to Saskatoon. La Loche, the closest nearby community, has a grocery store but, as in the reserve, the prices are much higher when compared to prices of similar groceries in larger cities. In the winter, Fort McMurray is only a 2-hour drive away via the winter road and many people from CW go shopping there. In addition to groceries and other essentials, shopping for clothing and other items is a major reason for mobility out of the community. As one person observed, "... because food is expensive here, and I will want to travel if I have a bit of money then I will get out of town just to get more stuff, for what I get here I get double out of town." [Community member 3]. A push factor out of the reserve is the lack of clothing and other supplies available in and near the community. The nearest grocery store is a Northern store in La Loche, CW does not have its own full grocery store, but does have a convenience store.

Saskatoon, North Battleford, Prince Albert, and Meadow Lake all have more affordable groceries as well as a greater range of supplies available. Another individual added:

Definitely shopping because it's so expensive in the north, I'm sure if you go to Northern or Centre Point [local stores in CW and La Loche] their prices are crazy and they often have sales but it's not the same, it's not a nice sale from Superstore [A grocery store found in larger communities]. Fort McMurray in the wintertime is 2 hours away or less because the local La Loche and CW people use that winter road. [Community member 6]

Cabin fever and entertainment were commonly-cited motivations for travel out of the community. The lack of recreational activities available in CW is a push factor out of the community; commonly reason for travel is activities for children, sports, and camping.

Saskatoon mainly for my girl, my daughter she plays volleyball all winter all year long right up till may. Right after she's done vball [volleyball] we travel to all her school tournaments and all her club tournaments mostly in Saskatoon.

[Community member 7]

Saskatoon, Fort McMurray, and Edmonton were common destinations for entertainment. And, community participants stated that during medical travel, entertainment and activities are also a part of those trips if there is time. Although shopping figured prominently in the interviews, the main reason identified by community participants was medical. As a category for this study, medical services include doctors' appointments, hospital visits, specialist appointments, and dental and optometrist consultations.

Well I have doctors appointment, when I have doctors appointment in PA, Saskatoon, Meadow [Meadow Lake], Battleford [North Battleford]..... Lately I'm going to PA, every 3 years I go to PA, I go up there for counselling

[Community member 8]

The community hosts a visiting dentist every few months but there isn't a regular dentist in CW or La Loche. Specialized dental care (surgeries, braces, etc) is not available in the community, but instead is accessed elsewhere. While there is mental health and counselling

support in La Loche (but not CW), due to the small size of the community a common sentiment felt by community members is the lack of privacy. Because of this, access to counselling services was cited as a reason for mobility out of the community. Depending on availability, community members travel to Prince Albert and Saskatoon for therapy appointments. La Loche's health centre has x-ray, lab and telehealth capabilities however specialist appointments and hospital admissions are scheduled in cities around Saskatchewan depending on availability of space. There is a medical taxi available for residents of CW and accommodations are covered through FNIHB for patients.

Family is another reason identified as both a stick and push factor out of the community. Family connections and staying connected to roots determine a major part of what defines "home" for CW residents. People travel to Janvier, Chard and Cold Lake in Alberta to visit and stay with family. When travelling to cities in Saskatchewan, for many people accommodations are not an issue because there are family members all over the province. A stick factor bringing people back into the reserve is family; this is especially true of individuals with addiction or substance issues. A community member told a story of her son leaving CW often for weeks at a time and coming back, "My other son he lives in PA now, took off about 2 weeks ago, he's got friends in PA. When he gets tired he comes back." [Community member 8].

Some leave the community to get away from addictive substances or to stay with family or friends that don't drink in Prince Albert or Saskatoon. Another major motivation for mobility is to maintain tradition. Many community members travel farther north to cabins, in order to participate in hunting and camping. There is a pilgrimage that takes place outside of Edmonton that the majority of the community attends every year.

Every year in July I go there for they have a pilgrimage in July. It's the third week in July. For the last 27 years I've been going there. A few times I missed because I went the other way. I like going there. This year I don't know if I'm going to go [Community member 8]

[At the pilgrimage] there's a lot of tradition as well too and there's a lot of other types of religion happening too like the Roman Catholic people will practice and then they'll have tea dances and some traditional stuff too and most of the prayers

are done in Cree language or the Dene Language and it's for a whole entire week and there's thousands and thousands of people camping there. It's just like a big wide open field, and people just go there and set up camp and it's just like a mini village set up for a whole entire week. [Community member 5]

Traditions and staying connected to the land are a major part of what defines home and contributes to mobility in and out of the community as both stick and pull factors (Figure 4.3). Employment opportunities are available in both Alberta and Saskatchewan outside of CW. These include weeks in and out of the community for temporary employment opportunities as well as permanent positions that require mobility out of community. Depending on destination and motivation, length of stays and patterns of mobility are diverse.

4.2.3 Patterns of Mobility

Mobility out of the community is common throughout the year, however I found that mobility patterns (including destinations), frequency, and routes change according to the season. In the summer, travel within SK is more common due to easier access via the provincial road and highway system. Generally speaking, travel to Saskatoon occurred throughout the year but some

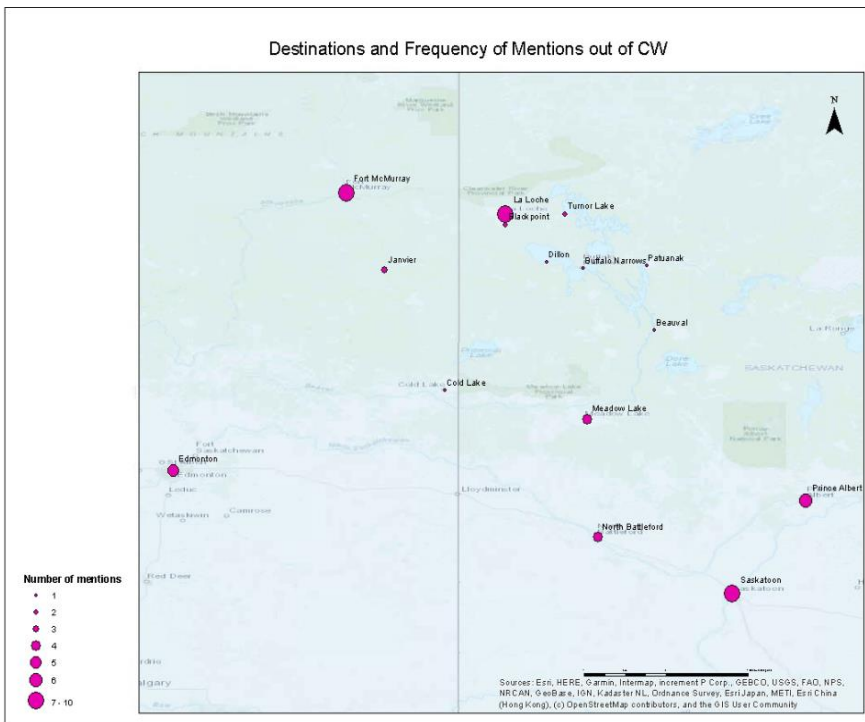


Figure 4.4: Map depicting the frequency of mentions for destinations by community participants

individuals travel to the city more frequently during the summer months. However, in the winter months the frequency of travel to locations in AB increases with the availability of winter roads. All the interviewed community participants spoke of a major increase in travel to Fort McMurray during winter months when the winter road is open (Figure 4.4). Driving into destinations in Alberta in the summer can take up to 10 hours or more, however in the winter travel time decreases to six hours or, in some cases, much less as seen by the winter road in Figure 4.2. However, there was no consistency between interviewees in terms of travel in the spring and winter. Some participants claimed no travel at all during Spring months while others mentioned that most travel occurs during Spring and Autumn.

Participants identified several different modes of travel out of the community. The most common was driving which was identified by all interviewed community members. The other modes identified were hitchhiking, taxi, and flying. During my visits in CW I noticed that hitchhiking is a common method of travel between La Loche and CW, and was also identified as common for travelling to other cities within Saskatchewan.

I used to hitchhike, my sister always got mad at me.....If I want to go to Patuanak now I'll look for a ride up to Beauval and my friend will pick me up instead of hitchhiking. [Community member 8]

If individuals are working for limited terms or temporarily in Fort McMurray or Northern Alberta, companies often fly out the employees, which requires only a 45-minute flight from La Loche compared to the 9-hour drive in the summer. If travelling for medical reasons, community members can request a medical taxi to their destination 24 hours before their travel date. As a general rule, duration of travel varied with the reason for travel. The most common answer for length of stay was two to three days (or a weekend) if travel was for shopping, medical purposes, sports, or leisurely activities. Weeklong trips were mostly identified for camping, visiting family, vacations, or work. Long-term stays were identified for work and family. The length of stays is especially important when considering continuation of TB care and avoiding treatment failure and is discussed below.

Through this study I found that mobility patterns are dependent on size of the destination and the distance from the community. This pattern is reflective of the gravity model of

migration, a theory derived from Newton's law of gravity, which states that attraction between two objects is proportional to mass and inversely proportional to distance (Colwell, 1982; Rodrigue et al., 2013). This theory can help to answer one of the main research questions about what kind of patterns of mobility there are out of a border community. Geographically, objects and mass are replaced by locations and important, so attraction or demand to a location is directly proportional to the importance of the destination and inversely proportional to the distance between them. Thus, the smaller the distance, the greater the frequency of travel. For instance, the distance from CW to La Loche is only 7 km, and this is reflected in the frequency of travel between these communities. At the same time, the City of Saskatoon, a more distant city of approximately 272,000, was also a key destination. In this case its attraction is due to its size as well as its relative importance in terms of resources, kin networks, and available shopping. Although there is a larger distance, mobility to Saskatoon is a necessity for community members of CW. This theory may also explain the lack of mobility to Regina, Calgary and other major cities in AB and SK due to the increased distance although these major cities also have the necessities such as healthcare, shopping, and resources available. The lack of mobility to these cities can be explained with distance decay in which the interaction between places decreases due to the increasing distance between them (Norton, 2009).

CHAPTER 5: FINDINGS OF MOBILITY AND HEALTHCARE

In this chapter I explore the implications of inter-community mobility on TB prevention and care based on a critical review of key TB documents and interviews with health providers in AB and SK. This chapter is organized in two parts; (1) the nature of TB care and prevention programming at the policy level and in practice, and (2) the role of mobility as a DOH. In part 1 I discuss the findings from a multi-level document review as well as the results of interviews with policymakers and health service providers, in order to better understand the reality of TB care in northern SK. I review documents generated at the federal and provincial (SK and AB) levels, as well as those governing current Indigenous rights and policies (Table 3.1). I then compare the findings from the document review to the findings from health worker interviews. Comparing findings from document review and health worker interviews allows me to identify and compare any differences that may exist between policy and reality. The findings from part one lead into part two, in which I discuss current programming at a national, regional and provincial level for mobile patients. By considering the results from Part 1 I can then assess the potential implications of mobility for TB case finding and programming. Finally, I consider the need to reshape the meaning of mobility in healthcare and implications of remote locations for access.

5.1 Tuberculosis Care and Prevention Programming

TB is managed provincially in Canada, with each province having its own set of policies and strategies for tackling the disease. National recommendations provided in the 7th edition of the Canadian Tuberculosis standard are available for health authorities and systems in all provinces and regions in Canada to use at their discretion. The recommendations are created based on previous research and evidence. While each province does follow the national recommendations, the organization of the healthcare systems in each province can be different. The recommendations provide the provinces with guidance but also with flexibility to meet local conditions. Flexibility in national and provincial guidelines are especially important in isolated and remote communities in which it may not be possible to closely follow national recommendations.

5.1.1 Current TB Programming and Recommendations

This section describes the findings about current TB programming and recommendation for national, regional, and provincial (Table 3.1). I compare differences between policy and reality of care throughout this subsection. According to the findings from the document review, the national TB guidelines recommend four tests if a patient is suspected of having TB in order to confirm active disease (Canadian Lung Association et al., 2014). These include chest radiography, sputum smear microscopy, mycobacterial culture, and Nucleic Acid Amplification Tests (NAATs). Chest radiography (or chest X-ray) is usually the first step but does not give conclusive results, thus needs to be combined with microbiological tests. The most common is examining sputum smears for organisms. NAATs is also used which detects genetic material of the microorganisms. At least three sputum samples are collected for testing. The standard for collecting is spot-morning-spot where an individual does a specimen at the initial visit, another in the morning, and another on the spot when they submit the morning one (Ndubuisi et al., 2016; Peralta et al., 2016). However, according to the TB Standards, this could have higher dropouts and is inconvenient for patients. “Same day” can be an alternative where two specimens are collected on the initial visit at least an hour apart. This method could prevent drop out.

According to the national recommendations smear testing is recommended for all individuals suspected of having TB. Within the national guidelines there are no other specific guidelines for the “initial” check-up but a site visit to the patient’s home is recommended. The national recommendations may act as a guide for biomedical tests allowing jurisdictions to follow their own method for an initial check-up with the patient. Although AB and SK do not have guidelines explicitly stated in the provincial guidelines health workers follow a prescriptive procedure for initial checkups, thus it is possible that there are internal policies I could not access. During my interviews, according to front line health workers, the initial check-up with a client suspected of having TB involves symptom inquiry, assessment of TB and tuberculin skin test (TST) history and arranging for sputum collections. The importance of protecting both the individual and the public was emphasized greatly throughout the interviews. Protecting the public may include isolation to some degree if respiratory TB is suspected. Isolation can include home isolation if conditions for home isolation are met or hospital isolation. However, during the health worker interviews some health workers were unaware of the home isolation conditions

outlined in the national recommendations. AB and SK also have different isolation protocols that are further explored in the next subsection.

The active treatment procedure is described in the national recommendations, which are reflected in the AB and SK TB guidelines. According to the national recommendations, if an active TB patient is confirmed, the treatment has two phases, an initial intensive phase which takes about 2 months and a continuation phase that lasts a varying length of time. Generally, the intensive phase recommends daily oral doses of isoniazid, rifampin, pyrazinamide, and ethambutol while the continuation phase can be daily or intermittent treatments. According to healthcare workers from both AB and SK, the duration can range from six months up to 18 months. The length of time of treatment varies according to risk factors, patient compliance, and other life and environmental factors. "...if they can take their doses all the time and they're diligent with it takes them 6 months or I've had [a] client go up to 18 months because they're missing so many doses." [TB nurse 1].

Currently, directly observed therapy (DOT) is recommended for all patients, and all jurisdictions should have the capacity in community to provide DOT. In the guidelines, DOT involves watching the patient swallow the medication and can be done by health workers or volunteers. DOT is recommended especially in populations that may have had higher rates of non-completion. While the technical definition of DOT is rigid, in the communities DOT is about building a trust and relationship with the patient. TB workers act as a point of support while simultaneously ensuring medication is taken diligently. DOT also allows for side-effect monitoring. In practice according to the interviewed health workers, DOT care is provided to the patient with flexibility; if a patient is mobile health workers attempt to make DOT available in their locations. Depending on circumstance, self-administered therapy (SAT) may also be arranged for patients. In both SK and AB, DOT is done by trained health workers rather than volunteers such as family members or friends.

Contact investigations involves interviewing TB patients about contacts, locations, and activities. The goals of contact investigations is to find other potential active and LTBI patients. Contacts are grouped into high priority, medium priority, and low priority. High priority includes close household contacts, medium includes close non household contacts, and low priority casual

contacts. It is difficult to determine exact period of infectiousness, but generally it is recommended to consider starting contact investigations from 3 months before the onset of respiratory symptoms. Once the patient is isolated, they are considered non-infectious. Face to face interviewing and multiple sessions are recommended in order to increase trust, an important consideration is accommodation of language and culture. Contact investigations can take substantial time and manpower; this may be especially difficult if contacts exist in multiple locations. According to healthcare workers the range of contacts can be as little as five all the way to 100 or 150 people. Multiple interviews are done with the patient in order to aid with recall. Often patients may not remember names or numbers, and healthcare workers rely on the community for information. A site visit is highly recommended within the Standards, and this is in reality a common approach, with DOT workers often accommodating clients by meeting them at home from the initial visit until the end of their treatment.

If during a contact trace, or during a TB TST or interferon gamma release assay (IGRA) test a person is identified to have LTBI, national guidelines recommend treatment on a case by case basis. The chance of LTBI becoming active TB is about 10%. Indeed, there are many factors that can contribute to this occurring as mentioned earlier such as exposure to detrimental circumstances leading and in turn poor SDOH. The chance of becoming active is also increased by comorbidities like diabetes mellitus, HIV/AIDS, silicosis, and others according to the national TB guidelines. Current standard in the national recommendations is nine months of self-administered isoniazid daily for nine months, the specific reasons for choosing self-administered therapy instead of DOT are not provided in the national recommendations. The most recently used treatment in communities according to the health worker interviews is now a four-month regimen of two days a week instead and depending on the patient and community it can be directly observed or self-administered prophylaxis. Prophylaxis treatment has a higher chance of successful completion with patient centered care and follow up, however this can be resource intensive especially in remote and rural communities. It was highly emphasized during the interviews that the doctor, patient, and sometimes communities are a factor in whether LTBI treatment is directly observed prophylaxis or self-administered prophylaxis.

5.1.2 Comparison of Alberta and Saskatchewan TB Programming and Care

Before I describe the differences between AB and SK TB care and programming, it is important to understand the differences in healthcare structures between these two provinces. In 2017 Saskatchewan transitioned from 17 health authorities to a single health authority, the Saskatchewan Health Authority (SHA). This structure is, superficially, similar to that of Alberta. The SHA is governed by 10 voting members from different locations in Saskatchewan. The objective of the SHA is “effective planning, delivering, and evaluation of all healthcare programs, on behalf of all the residents of Saskatchewan” (Saskatchewan Health Authority, 2019). Since the amalgamation there are no officially specified health zones like that of AB in SK but there are unofficial zones or health networks (Figure 5.1). In Saskatchewan in addition to the SHA, the Athabasca Health Authority services five communities, Black Lake, Fond Du Lac, Stony Rapids, Uranium City, and Camsell Portage (“Athabasca Health Authority”, 2006). Alberta with its similar system has Alberta Health Services (AHS) board overseeing the entirety of the province. Alberta is divided into five major zones which include North, Edmonton, Central, Calgary, and South zone (Figure 5.1) (Alberta Health Services, 2016). North Zone is the largest geographical area and include both Janvier and Fort McMurray. The differences in TB policies and programming between SK and AB stem from differences in structure of healthcare described above. As well as, differences in healthcare providers, and some TB treatment processes, these are further explained in this chapter.

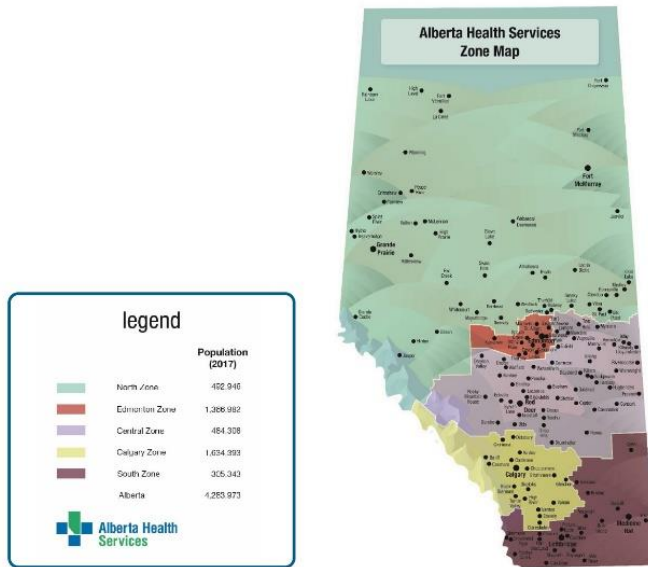


Figure 5.1: Alberta Health Services Zones (Government of Alberta et al., 2014)

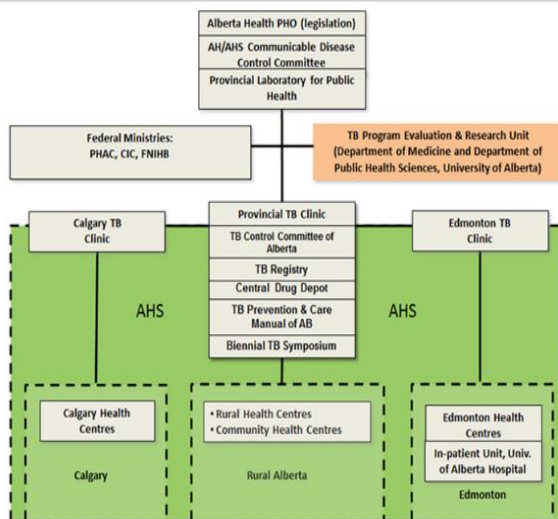


Figure 5.2: Organization of Alberta TB Prevention and Control Program (Government of Alberta et al., 2014)

In the document review, *Tuberculosis in Alberta Surveillance Report* provides a detailed structure of TB programming in AB. There are three TB clinics within AHS, with two brick and mortar and one virtual clinic (Figure 5.2). The virtual clinic handles rural AB and is managed by the same physician that works out of the Edmonton TB clinic. The Edmonton central TB clinic receives all patient information, referrals, x-rays and the physician makes recommendations

based on the information they receive. In SK under the SHA, TB Prevention and Control Saskatchewan provides TB care and programming for all Saskatchewan residents. According to health worker interviews some participants explained that SK has three TB program lead nurses for “various zones”, and under the *TB Program Worker Handbook*, TB services offices are specified under central TB program, NITHA TB program, and South TB program. The various zones are not available in the documents I analyzed, however north, central, and south are the major health zones according to health workers. NITHA is a transfer organization that works specifically with Northern First Nation communities, this is further explored in the next subsection.

According to both the health worker interviews and the provincial TB documents, both AB and SK follow the same active treatment of two months of intensive phase and then a continuous phase as outlined in the 7th edition of the Canadian Tuberculosis Standards. As well, LTBI treatments are the same in both provinces although the national standards have not yet been updated to the most recent LTBI treatment change. Specifically, for active TB treatment, in the document review I found that both SK and AB provide the same treatment of intensive and continuous phases as well as the same LTBI treatment. Currently, the SK TB program is undergoing major changes, and therefore a complete list of policies and procedures is not yet available. Both provinces use DOT in order to maximize treatment adherence and completion, however there are some differences. *Tuberculosis Prevention and Control Guidelines* in AB I found the following:

Initially the PHN, Community Health Nurse, or DOT worker always provide for the delivery of medication to the patient and watches him/her swallow them. Once a patient is established on DOT, another responsible person in the community (teacher, CHR), often can be trained to supervise the taking of medication. (pg. 118)

In reality in AB, according to the health worker interviews, for rural First Nation communities the practice of DOT is done by a nurse and community health representative (CHR), and if the total workload is above a certain threshold the community can apply for funding to the region for a DOT worker. However, in SK a registered nurse visits with the TB

worker, and from there on the TB or DOT worker always provides DOT. In Northern First Nation communities in SK there are DOT workers in the community and additional support from NITHA is provided. In section 60 of *TB Prevention and Control Saskatchewan Clinical Policies and Procedures* (Table 3.1) in SK, home isolation is common during the infectious period rather than isolation in a treatment facility. Isolation in a facility may be necessary depending on the patient's condition, a negative pressure room may be needed due to cavities in the lung.

.....if the patient is really very ill and if he needs to be isolated, there is usually a negative pressure room. Where the patient is isolated and only seen by the health staff who has to wear certain protective equipment. But for example in La Loche there is no negative room but the patient is isolated as much as they can. The patient will be transferred to Saskatoon or PA either Victoria hospital (in Prince Albert) or St.Paul (hospital in Saskatoon)...[How do they decide where to transfer patients?].Depends on vacancy in the ward... [Physician 1]

Although home isolation is a recommendation for SK it was identified by health workers that patients do not always follow this recommendation:

...most of the time people don't follow those rules, I shouldn't say most of the time, I see a lot of people who we give direction about quarantine go out in the community, even when isolation period is still in effect. [TB nurse 2]

Then we also encourage them to self-isolate especially with infectious TB or the smear positive ones, the nurses advise them to stay home, actually for 2 weeks of the medications when the individual transmitting the disease would be very little [Physician 2]

The importance of home isolation during the infectious period was emphasized by many of the health worker interview participants in SK. According to healthcare providers AB utilizes less home isolation than SK. Most clients are directed to the TB unit at the University of Alberta:

So in AB we're not practicing a lot of home isolation in First Nation for number of reasons, definitely the crowding piece is one of them. So most of our clients if they're infectious go to the TB unit of U of A (University of Alberta) , so they'd

be non-infectious that's usually 3 weeks (ish) so the other reason is that culturally it is difficult for people to turn people away from their homes, visitors and what not. yeah, so there is a few reasons that it isn't... [TB program coordinator]

Although home isolation is not followed as much as SK, in policies, AB has recommendations for both home isolation and hospital isolation in the *Tuberculosis Prevention and Control Guidelines*:

If individuals with infectious TB can be safely managed in their home environment without danger to themselves, their family, or the general public, AHS central TB Services and/or the local outpatient TB clinic, will encourage and support this. If isolation in the community is not appropriate or feasible, hospitalization may be required. (pg. 98)

In reality as stated above by TB program coordinator, home isolation may not be possible in remote communities due to overcrowding in houses. Thus, while AB policies provide guidelines for home isolation, they follow hospital isolation more. The difference between SK and AB for isolation guidelines, and patient compliance to isolation guidelines may have implications for TB transmission especially in regard to mobile patients.

Generally, AB and SK have the same treatment procedure for TB, however the smaller differences in health provider roles such as the use of DOT workers for DOT in SK but CHRs and/or nurses in AB, differences in health care structure discussed above may contribute to the impact of mobility on TB care and prevention programming. The implications of these differences are further explored in section 5.2 of this chapter. In addition to the differences between the provinces, another layer exists in TB programming in rural and First Nation communities in both provinces.

5.1.3 TB Programming in First Nation Communities

In SK TB control falls under different jurisdictions between on-reserve and off-reserve, in which on-reserve is federal and off-reserve is under provincial jurisdictions. However, there is essentially no difference in the TB programming because it is centrally coordinated by a provincially funded TB control program in Saskatoon. Thus, according to one health worker

interviewee, “the program is the same, policy guidelines for prevention, treatment, contact and also diagnosis is pretty much the same.” [Physician 2]. A major difference identified by this physician is education, in which the content provided to Northern First Nation communities may be more culturally appropriate and tailored to a First Nations demographic. Many First Nation communities in northern SK are remotely located and isolated, and therefore their social conditions and environment differ greatly in comparison to urban settings. Health worker interview participants and *Health Canada’s Strategy Against TB for First Nations On-Reserve* have identified risk factors such as overcrowding, poor nutrition, lack of access and resources, other diseases, mental health and addictions for remote First Nation communities that may be different from urban communities. Lack of access and resources in remote First Nation communities could cause delays in patient transportation, and difficulties accessing diagnostic facilities. A recommendation from Health Canada’s Strategy Against TB for First Nations On-Reserve is to “develop tailored approaches to reduce incidence of TB where there is evidence of ongoing high incidence”. Thus, there are some differences between CW (a First Nation reserve) and urban city settings, such as organization of health services, availability of clinicians, and relationships with health providers in addition to the differences in SDOH.

Health services differ for on-reserve First Nations peoples in which First Nations health is managed under the FNIHB. FNIHB’s mandate is to “(1) ensure the availability of, or access to, health services for First Nation and Inuit Communities, (2) assist First Nation and Inuit communities address health barriers, disease threats, and attain health levels comparable to other Canadians living in similar locations, and (3) build strong partnerships with First Nations and Inuit to improve the health system”(Government of Canada, 2013). Thus, in SK and AB, FNIHB is the health authority for all First Nation communities. However, in Northern SK, NITHA acts as a transfer organization under FNIHB to coordinate and provide care for all northern First Nation communities. NITHA stands for Northern Intertribal Health Authority and they are a First Nations Organization that is funded through FNIHB. NITHA serves 33 First Nations in northern SK (NITHA, 2020).

So we offer (have) MHOs (Medical Health Officers) and public health, we have environmental health, health promotions, we have an epidemiologists, public health nurse, HIV, TB, we have a community health status surveillance unit

which is tobacco strategist, dietitians health and we have an IT (Information Technology) department. We are managed by an executive director so basically our mandate is that we are guided by our four partners to provide service to and servicing First Nations [TB nurse 3]

Many northern First Nation communities are remotely located and NITHA provides extra support:

NITHA is a third level organization, we don't offer service to the community but for our TB program we're supportive and we actually do first level, so the community has nurses that are uncomfortable or inexperienced with TB and actually do contact investigations, we train TB workers, we train new community health nurses. We participate in Treaty days and health fairs at the school, education and we try to provide. And of course, we have, we collect data and information so we can provide accurate analysis of information of what's going on to the communities. [TB nurse 3]

In AB, FNIHB is directly involved in healthcare for First Nation communities and provides funding and support when needed. In northern SK First Nation communities, TB is managed through NITHA. Often nurses and other healthcare providers in remote First Nation communities have many roles in addition to TB care and may be overburdened by the workload. Through the health worker interviews I found that NITHA provides the training for TB workers, assists with contact investigations, and troubleshoots and intervenes when needed with increased cases or if there is a lack of capacity in communities. There are three TB nurses and one MHO involved in the TB program, usually NITHA acts as a third level organization however the TB program provides direct first level support. First level is direct support to community member, and third level are services provided to the Community Bands and Tribal Councils. Second level was not discussed in interviews. Third level services include disease surveillance, communicable disease control, health status monitoring, epidemiology, research, planning, education, training support and other services. (NITHA, 2020). At the third level support NITHA provides training for TB workers for DOT and payment in CW.

They (NITHA) come in person and do it, and then the TB workers are now paid through NITHA whereas before it used to be through Health Canada. They took so long to pay, like Health Canada that we almost lost our TB worker that's been with us for quite sometime and she was at the brink of saying I don't know if I can handle this. So then NITHA kind of worked more so with that [Public Health Nurse]

NITHA is a major support organization on reserve in CW and helps ease the burden on TB workers and nurses in the community. For first level support, a TB nurse from NITHA visits CW a couple of times a month and sometimes takes on the community nurse role depending on workload. NITHA works solely on-reserve because it is funded through FNIHB and reports to FNIHB public health MHO in SK. Therefore, there is a jurisdictional difference between CW and La Loche, a community only five minutes away from CW. While the two communities are closely related through geography and kinship networks, the two communities are under two different jurisdictions. Therefore, TB patients in La Loche and CW have their own DOT workers. CW has a health center but is not a treatment center, “Well first of all this health center is not a treatment clinic meaning we do minor dressings, we don't check the ear or check the eyes because we are not a treatment clinic” [Public health nurse (PHN)]. The health center focuses on public health and oversees homecare according to health providers at the center. La Loche has a full health centre with access to comprehensive lab work and radiology. La Loche also has a fulltime TB program and more capacity to treat patients. Health workers in CW and La Loche work closely together, although the TB treatment is done separately in each community. While in the document review, SK policies had no prescribed line of communication, but it does occur between the TB nurse from La Loche (provincial), CW public health nurse (FNIHB, federal), and NITHA TB nurse (FNIHB, federal). Often possible TB patients from CW may go directly to the La Loche health center, or reach out to the nurses in CW.

There's always that communication with [TB nurse 2], she's a TB nurse, right? she'll call me and say we do have a couple of people that live on reserve and I go look for em (them), otherwise if she doesn't contact me [NITHA TB nurse] is sometimes here. So [NITHA TB nurse] is aware that there is an active case in La Loche so she'll often go see [TB nurse 2] and work alongside her, and then

[NITHA TB nurse] comes here and says we have like 5 that lives on reserve so that's the first time I'm hearing about this because [TB nurse 2] will mention to [NITHA TB nurse] and doesn't have to double, you know I get the information anyway. [PHN]

CW has a part time DOT worker that is supported by both the NITHA TB nurse and the CW PHN who are both supported under FNIHB and federal jurisdiction. Patients often travel between CW and La Loche, and although they are in two different jurisdictions with separate TB programming the communities are almost one due to proximity and the strong relationships that exist between the two. While there is communication between La Loche and CW, there is no prescribed path of communication. As stated above, there is sometimes direct communication between the communities' nurses and sometimes indirectly through the NITHA TB nurse. Having a prescribed path of communication is especially important because the two communities are in two different jurisdictions, La Loche is funded through provincial health and CW is funded through federal.

A major characteristic that exists in remote First Nation communities is the relationship between the community and its frontline healthcare workers. Because the communities are close-knit, the front-line healthcare providers are often members of the community. In interviews, the importance of trust and close relationships was apparent, "they're (patients) are aware that I'm here, and they'll just bypass the clinic and they'll come directly to me or one of the TB workers". [TB nurse 2]. If a patient suspects TB, they'll often approach a health worker directly. There is also a relationship that is built between the DOT workers and TB patients in the community. TB program workers are taught to be confidants for the clientele. This increases trust and the chance of patients informing them about travel plans. The health workers also rely on the community during contact traces, often a patient may not know all the information but the people in the community know everyone.

5.2 ROLE AND IMPLICATIONS OF MOBILITY

Chapter 4 outlined the importance of mobility in CW Saskatchewan. CW being a border community, many of the residents are mobile out of the community as a major part of their activity space. This second part of chapter 5 explores the role of mobility in health and TB care

and prevention. The first part identifies what the major implications of mobility may be. The second part explores the reality of TB care for mobile patients and on-the-ground care for mobile patients. Mobility needs to be considered for policy and management of individual and population health especially for smaller geographies such as northern and rural communities and border communities. Mobility was identified as very common by community members as discussed in Chapter 4. As well, patient mobility was identified as very common by both AB and SK health workers.

Some people never feel sick enough to stop or really change their behavior other than that maybe they have a nagging cough they can't get rid of, so that's what causes them to present not necessarily, like they can't do their work or play like normal or it may be slowing them down but not as readily, it kind of varies. [TB Program Coordinator]

Among others, patients cross over different jurisdictions from on-reserve to off-reserve and inter-provincial. Canada's Strategy for TB in Reserve identify First nations as a mobile population, and this characteristic needs to be considered when creating TB care and prevention programming. Implications of mobility are identified in both policy documents and by healthcare workers. Thus, this section explores why mobility and changes in geographical location should be considered as a determinant of health.

5.2.1 Implications of Mobility

Increased mobility may make contact investigations difficult. Contact investigations require many hours of work and the spill over into other provinces can be difficult according to TB nurses and workers. Increased mobility could lead to incomplete or interrupted treatment, for both active TB and LTBI treatment. Interrupted treatment could lead to drug resistance and TB relapse. Both SK and AB follow DOT and thus each patient has their own TB worker. However, with mobility continuation of care is possible with clear communication because AB and SK both follow the same TB treatment as outlined in national TB standards. Depending on the length of time away from the home community, DOT workers may need to change. It may be difficult to build trust with clients if multiple DOT workers are involved. Although communication between TB worker and patient varies, according to health workers many patients communicate

travel plans ahead of time, although this is not always the case. It is not only the health worker's responsibility to ensure continuation of care, but it is also the responsibility of clients to share travel plans. However, communication about travel plans is not always possible in communities with transient populations, "Yeah so within the province it happens all the time, people are very mobile." [Physician 3]. It was a common sentiment among the health workers that mobility levels are high, and transient populations are harder to track.

We try our best, some people do end up falling through cracks still because it's just it can get quite complicated. Especially if someone is taking off to AB and then we finally realize a week or two later where they are. And we get phone numbers and stuff, and so it can get quite complicated and difficult to deal with.
[TB Nurse 1]

Trust is a major aspect of DOT care, and patients are more likely to share travel plans if there is an existing foundation of trust and communication between the healthcare provider and the patient. If a patient does not trust the DOT worker or healthcare worker taking their history they may not be as forthcoming about their past travels. This may be especially true if addiction and illicit drugs are an issue.

Not infrequently the patient may not tell anyone that they're going and then things kind of unravel..... for whatever reasons they may not be forthcoming about the fact that they just spent the last month in Janvier, they may not for whatever reason, it depends a lot on who's taking the history and how comfortable they feel about sharing information [Physician 4]

So someone will be in La Loche, and then the next thing you know they're going to be in Prince Albert for a week for whatever reason. And then we follow them quite easily. Then the TB worker will find out that they're not, ideally they'll tell us a head of time. And that often happens but it doesn't always. And if that doesn't happen the TB worker will tell us they're gone and find out where they went to PA. And find out how to track them down in PA (Prince Albert). It's much easier when people have cell phones obviously but again not everyone does and then we connect with them and we provide either with latent disease or active disease, we

tend to then make the prescription and DOT available wherever they are.

[Physician 3]

Although many patients are forthcoming about travel plans, it is not always the case according to the physicians I interviewed. Finding patients is especially difficult with multiple jurisdictions and lack of communication between the patients and health care workers. An underlying cause for the lapses in communication may be lack of awareness and education around TB in communities. As TB has decreased amongst the general public, educational material is not as readily available for teachers:

There's not enough education for our children.....as far as our school goes as teachers we teach everything, sexual health, we teach everything, we don't have inter-agencies that we can call on saying I'm doing a unit on sexual health can you come in and talk about STDs (sexually transmitted diseases)? We don't have that option; I have to go and do my own research if I'm teaching about something.

[Community Member 5, teacher]

Thus, increasing both patient education and general education in schools may help raise awareness about TB. There was also a great emphasis among participants on the range in variance for care, self-administered therapy is sometimes arranged for a short period of time depending on the patient although DOT is preferred. Implications of mobile patients and travel need to be accounted for within policies and programming for TB. From the interviews it became apparent that mobility is a complex phenomenon. Mobility is further complicated by various issues affecting people of CW such as addiction, disease prevalence, and poor DOH. While policy specifically regarding mobility is important, it is also important to understand the multifaceted nature of both mobility and TB.

5.2.2 Current TB Programming for Mobile Patients

Inter-provincial mobility was identified as common by all community members. Mobility out of communities is identified as common in *Health Canada's Strategy Against TB for First Nations on Reserve*, and in the 7th Edition of *Canada's TB Strategy*. Within Calls to Action in the TRC, there is a call for the federal government to “recognize, respect, and address, health needs

of off-reserve Aboriginal Peoples” to address jurisdictional disputes. While the multiple jurisdictions of healthcare and the challenges associated with this are addressed within the *Health Canada’s Strategy Against TB for First Nations on Reserve*, currently the 7th Edition of the Canada’s TB Strategy doesn’t have specific policies for mobile patients. However, some recommendations are given. Within the *Health Canada’s Strategy Against TB for First Nations on Reserve* under theme one, element 1.5a, it states that it is crucial to “identify challenges and implement corrective actions as necessary for treatment interruptions and failures, patient mobility and seamlessness of services, disease relapse and drug resistance.” This is marked as required for regional programs, communities with front line health care services, and communities with ongoing high incidence or recurring outbreaks. *Health Canada’s Strategy Against TB for First Nations on Reserve* suggests reporting be standardized across jurisdictions. There is a call for partnerships and programming through consideration of local epidemiology. Within the national guidelines, there aren’t specific policies for mobile patients, but recommendations are available. For self-administered LTBI treatment it is recommended that the patient should not have more than a one-month supply, however if a patient is travelling exceptions can be made. Coordination, follow-up arrangements, and communication between health jurisdictions is recommended for homeless populations, remote communities, and First Nations populations. Along with the national recommendations, each province and territory in Canada as identified earlier has TB strategies and programming.

The Saskatchewan TB strategy identifies mobility as a phenomenon to be addressed within care. A collaborative approach is suggested that includes the creation of an inter-provincial TB working group. The prairie inter-provincial TB working group has members from TB control, FNIHBs of SK, AB, and Manitoba. Currently in development, this group is meant to provide a place to share information about mobile patients and collaborate on strategies. Although the intentions of the TB working group are to increase collaboration and coordination between jurisdictions, burnout of small community nurses both on reserve in CW and off reserve in La Loche needs to be considered and supported.

[TB nurse 2] and I are part of this TB working group model, I'm so confused. It's their trying to get a better system going, they actually we were hoping there

would be a different community instead of here because Pathways is already here.
And then there's this working group for a new TB model [Public Health Nurse]

Alberta does not appear to have specific programming or recommendations regarding mobile patients and inter provincial policies within the *TB Prevention and Control Alberta*. However, it is important to note that there may be policies and guidelines that are not articulated in the public documents I accessed for this thesis.

During the interviews, I asked healthcare workers from both AB and SK about the procedures involved with care for mobile patients. Although there aren't specific guidelines or policies in place for mobile patients with TB, most health care workers follow a similar communication procedure for mobile patients (Figure 5.3). Generally, when a patient is travelling from on-reserve to off-reserve, or in this case from CW to La Loche, depending on the duration of time the files do not get transferred. Rather, the TB worker from CW may reach out to the patient that has travelled from CW directly and do DOT. However, if a patient is moving to La Loche and changing residence permanently the files may get transferred and a La Loche TB worker may take over. For patients from CW travelling from SK to AB, and vice versa the process identified by health workers was mostly consistent. If a First Nations patient from CW informs their TB worker about future inter-provincial travel, the TB worker would then contact the responsible supervisor (often a community nurse) who then contacts TB control SK. TB control SK then contacts AB TB services in order to transfer care for the patient. Similar to off-reserve, a new TB worker or nurse will take over for DOT. There may also be communication between nurses or the front line workers in the communities. However, the line of communication between front line workers was not always clear within the health worker interviews. As a remedy, one nurse noted that "often times once a client is moving a lot then I

would encourage the two nurses at the community level to be communicating” (TB Nurse 1), this is shown by the dashed lines in Figure 5.3.

Keeping in mind the current procedures being followed in communities, and the discrepancies in current policies there need to be changes to consider mobile populations better. However, a major issue identified was the lack of capacity currently available for creating new policy:

...the demand for policy and implementation is sort of well in excess of our capacity. So we have to prioritize, and therefore if something is generally working well and it doesn't have a policy, it gets a lower priority because then we're focused on the policies that aren't working well. [Physician 3]

In order to prioritize creating new policy and inter jurisdictional programming, the way mobility, space, and place is approached in research and DOH needs to be reconsidered. Currently the Canadian DOH considers physical environment, however mobility and geographical location are not explicitly given priority. Thus, extending determinants to include geography and the way

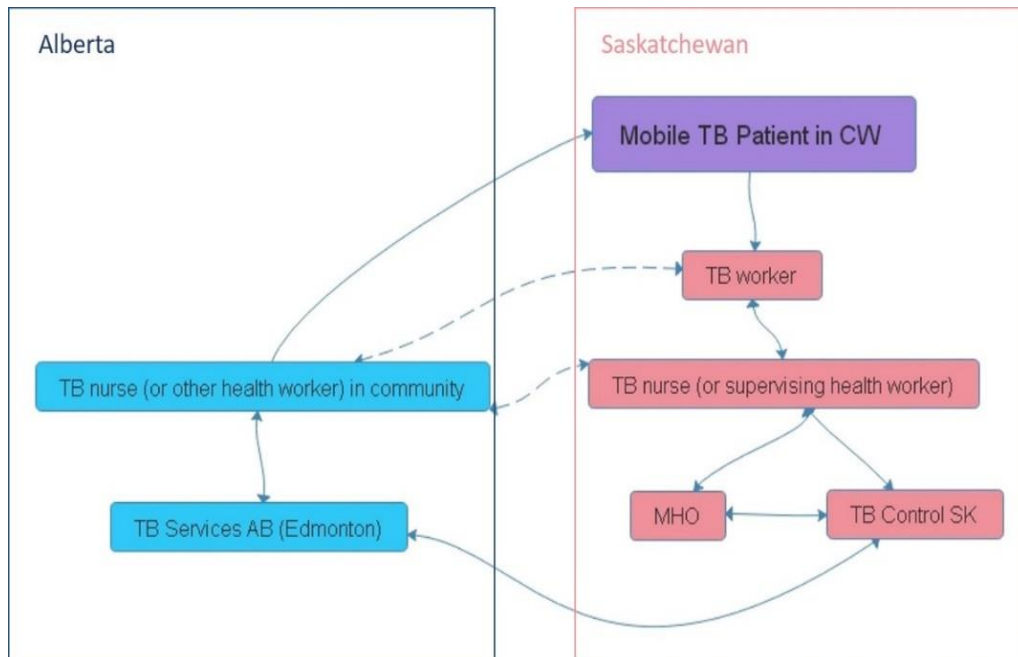


Figure 5.3: Line of communication from SK to AB for First Nations TB patient travelling from CW to AB destinations. Solid lines show consistent communication, dashed line shows inconsistent and nonregular communication

people move through space is important. People are not stationary, and thus DOH, policy, and

programming need to consider this as well. Chapter 6 further explores recommendations for TB care and prevention programming for mobile patients and communities.

CHAPTER 6:RECOMMENDATIONS AND CONCLUSION

The purpose and objectives of this study were to determine the potential impact of inter-jurisdictional mobility of First Nations people on TB and Prevention and Care programs. The findings for the three major objectives and research questions are outlined throughout Chapters 4 and 5. I used an instrumental case study approach centred in one First Nation community in SK in which the phenomenon of inter-jurisdictional mobility and impact on TB programming is the focus. In the preceding chapters I found that mobility is necessary for the members in CW. The border community is isolated geographically and thus mobility is a necessity for accessing resources, entertainment, kinship, medical care, employment opportunities and educational opportunities. The many destinations identified out of the community involve multiple jurisdictions, including inter and intra provincial, on-reserve (federal), and off-reserve (provincial). Mobility is also seasonally variable. Mobility out of CW to AB increases in the winter with the opening of winter roads thus crossing provincial jurisdictional boundaries. In turn, this movement has implications for TB care.

While the active TB and LTBI treatments are largely consistent for both AB and SK, there are some differences in structure and programming. As outlined in Chapter 5, both AB and SK use DOT but SK utilizes home isolation more frequently than AB which isolates patients in hospital. SK also has a transfer organization, NITHA, for treatment and care of First Nations patients with TB. These differences, along with differences in healthcare personnel and relationships with health workers has implications for mobile patients travelling between SK and AB. As explored in Section 5.2, while there aren't specific prescriptive policies and programming for mobile TB patients there is an informal path of communication between jurisdictions. Thus, for this final chapter I make recommendations based on the findings in Chapters 4 and 5. The recommendations are in two major parts: (1) general programming and policy recommendations, and (2) in-community interventions focusing on smaller geographies and epidemiology. Part two of this chapter concludes by discussing the possible implications for future directions with this research.

6.1 RECOMMENDATIONS

The major aspects of treatment that need to be considered are continuation of care, treatment success, and contact tracing. While it is important to have a successful active TB treatment program, it is also important to consider other aspects involved with TB and how mobility may impact these. Therefore, policies and programming should not only be determined based on the treatment process, but must also be taken into account educational programming for both patients and school system, initial checkups, follow ups, communication, LTBI treatment, and proper continuation of care.

6.1.1 Inter-jurisdictional programming and policies

As discussed in section 5.2, there are currently recommendations in place but no clear-cut policies for accommodating mobile patients with TB. The recommendations provided here seek to address this gap and are focused on formally improving coordination and communication between health jurisdictions. While recommendations allow communities the freedom to create their own policies, currently there is a lack of continuity and availability of inter-jurisdictional programming and policies. During the interviews, many of the health workers emphasized the importance of increasing coordination between provinces. The inter-provincial TB working group in Saskatchewan as discussed earlier is a group in its preliminary stages which includes members from SK, AB, and Manitoba, with the goal of increasing collaboration between jurisdictions. Although still in its beginning phases, this may be an example of the type of inter-jurisdictional programming that is needed in order to tackle TB in the face of interprovincial mobility. Inter-jurisdictional programming should aim to create a platform for exchanging information and ensuring continuity of care for patients. Such a structure must cover not only the margins of the provinces, but further into the provinces as well. There needs to be a structure of cooperation in place not just for inter-provincial partners, but between other jurisdictions within the province such as patients travelling between on-reserve and off-reserve jurisdictions, which may be as short as travelling 5 km to 100+km to urban centers in the province.

When creating inter-jurisdictional programming or agencies, it is important to listen to community voices. The community voice will help create a better “picture” of what mobility looks like within communities, while addressing community needs. Given that mobility includes

multiple jurisdictions, all surrounding communities within the region should be included in discussions. Creating a platform for coordination may also lead to an understanding and accommodation of the differences that may exist between organizations and communities. For example, the training of TB workers may differ between provinces leading to different experiences for mobile patients. Although within the scope of this project I could not attain a full description of training within SK and AB. SK has the transfer organization NITHA which provides training for DOT workers and nurses in reserves. AB does not have a transfer organization, thus it is possible that training may differ between provinces. An inter-jurisdictional group platform would allow the different jurisdictions of health systems to standardize or fine-tune best practices for TB.

An impediment to adopting a model of cooperation may be understaffing and turnover; staffing challenges may be especially significant in remote communities. Many of the nurses, doctors, and front-line health providers in remote communities emphasized the many roles that they must take on, the idea of burn out was repeated throughout the interviews with health workers from both La Loche and CW. Inter-jurisdictional coordination and programming are needed to create a platform for different providers such as NITHA, FNIHB AB, and other health systems to work together, however this may not be possible without increasing human resources and structural and systems capacity within communities. Organizations such as NITHA are a model for policies increasing capacity to meet demand is found on the SK side, they provide additional capacity by sending nurses into the reserve as needed. However, in order for a trusting relationship to be built between patients and healthcare workers an ongoing presence in the community is important as well. A long-term plan should reflect this by increasing hiring within the community and by providing incentives and additional access to educational programs such as nursing or for young adults entering post secondary schools. Given the close connection to the land and CW that community members have, creating specific educational programming and training for students in the community may contribute to retention of health workers. The idea of “home” was a major stick factor for community members to come back to CW after travelling.

Continuity of information exchange is an equally important consideration. CW and La Loch are closely related by both geography and kinship and exist functionally as virtually one community. However due to jurisdictional issues NITHA operates in CW but not in La Loche

(off-reserve). Under the current patchwork system, NITHA TB (federally funded) nurses and La Loche TB nurses (provincially funded) are in contact about current TB cases, however La Loche TB nurses and CW TB workers are not always in direct contact. Important information gets exchanged, but the procedure for the information exchange is neither clear nor mandated which may enable some cases to fall through the cracks. On a larger scale, this is also a potential limitation for TB control between the provinces. If a patient is travelling from SK to AB, even though there is coordination through the two provincial TB services there is not always direct communication between nurses from the home and destination communities (Figure 5.3). The lack of clarity in the path of communication may lead to a breakdown in continuity of information exchange about patients, and specifically mobile patients. Towards resolving this, the creation of a database, or a standardized online system for communication of results and treatment status between the two provinces may be helpful for both TB health workers and all health services in Canada in general. The dual arrangement of TB management for First Nations people adds additional complexity from the standpoint of health jurisdictions, as overall health for First Nations on reserve is a federal responsibility, however management of TB is province-based. Moreover, Canada's decentralized health system doesn't follow standardized reporting, although if a database were to be created privacy and ethics needs to be carefully considered (*2010 Spring Report of the Auditor General of Canada*, 2010; Goldman, 2019). The Auditor General's report states that it is each province and territory's responsibility to develop their own electronic health record (EHR). While provincial programming is important, decentralizing the EHR plans will further impede inter-provincial collaboration. Therefore, standardized reporting with the maintenance of a national EHR may increase communication and ensure seamless treatments for transient patients.

In order to maintain continuity of care and clear inter-jurisdictional cooperation and communication, there need to be policies between provinces establishing the line of communication. As outlined in Figure 5.3, there is sometimes direct communication between TB nurses and TB workers between provinces. Both provinces report to TB control and services of each province about mobile patients, however within the TB strategies in both SK and AB the process of communication is not established. While policies need to be flexible to meet circumstances on the ground, health workers I interviewed called for something more defined for mobile patients. They also indicated that there is a need for direct and indirect communication

between communities in the two provinces and having clear policy to direct that communication would facilitate that. However, during the interviews I asked why the policies aren't yet established and as stated earlier it was emphasized that the demand for policy is greater than current policy building capacity. Thus, if provincial policies cannot yet be established, policies and programming for smaller regions may be a good starting point for addressing mobility.

6.1.2 In-community interventions

Provincial policies and programming are important, but during both community and health worker interviews the interviewees emphasized the uniqueness of communities. Each community has its own demographics and local characteristics. In order to address the issues associated with the system's potential inability to accommodate mobility of TB patients, it is important to have programming and policies tailored to individual communities or smaller geographies. Border communities have higher levels of mobility across the province; for example, in the winter people are highly mobile between CW and Fort McMurray. Non-governmental projects focussing on border communities, such as our Pathways project, may help in the process of developing programming for regions with high inter-provincial mobility. A network of communication between these communities would help minimize the chances of treatment failure, in terms of individuals with active TB not receiving treatment, for travelling patients. Having consistent meetings between these border communities and constant communication helps front line health workers stay in contact about mobile patients. However, such conversations should not be limited to those employed in the health care system, as community members may often know more information about patients than the health workers. This is especially true if nurses are visiting rather than residents in the community.

While having visiting nurses and support is an important factor for delivering effective TB care, in communities such as CW and La Loche trust in the healthcare system can be low. Therefore, increasing capacity and creating health training and employment opportunities in the community is important. By increasing the number of local health workers and TB workers in the community, patients are more likely to talk to and trust their health providers. This is especially important for DOT workers, as many of the interviewed health workers indicated that building trust and a relationship with the patients is an important aspect of being a DOT worker.

To increase compliance and treatment completion, video DOT (VOT) with the same DOT worker may be a good option as they have been found to be successful in areas with social and geographic barriers (Fraser & Keshavjee, 2019; Richardson et al., 2014). However, VOT may not be a viable option given the current infrastructure especially in remote areas with poor internet access, such as Garson Lake, Saskatchewan, or if patients are visiting remote northern areas and worksites.

Creating more sensitive policy and programming, and increasing capacity are potentially important to the system, however community interventions must also focus on the patients and the community itself. An important avenue of intervention towards eradicating TB in high-incidence communities lies with education. The WHO *End TB Strategy* emphasizes the importance of engaging communities and channeling information. As discussed in the previous chapter, it is evident that age-appropriate educational material concerning health and disease in general, and TB specifically, is lacking. University of Alberta and University of Saskatchewan created *Teaching Tuberculosis a Resource Guide for Aboriginal and Non-Aboriginal Youth* in 2010 as a teaching guide for teachers, schools, educators, and community health nurses (Long et al., 2010). While this resource guide is freely available for use, teachers may be unaware of it and need to be made aware of the existence of resources such as this. Increasing the availability of educational material for students, and by extension community members, will help increase awareness of TB, and other infectious diseases. Fundamental advice such as providing information about the consequences of sharing drinks, covering one's mouth when coughing, and how diseases are transmitted, are an important aspect in helping people prevent the spread of diseases, notably TB. Many of the health workers indicated that for some patients TB is not the biggest concern due to other issues such as addiction, lack of employment, and low-income status, which were seen to take priority. In part this lack of priority may reflect limited experience. In keeping with our existing understanding of the disease, community interventions need to focus on TB as a disease created by social conditions and provide a pathway forward for improving living conditions. By focussing interventions on improving DOH based on individual community priorities, we may have greater success in preventing and perhaps eradicating TB at the community level, over the long-term. One prerequisite for developing these effective community-specific TB policies and programming interventions in border communities with

highly mobile populations is further research in order to better understand local conditions. This thesis provides some insights into how, and why, this research may be undertaken.

6.2 IMPLICATIONS FOR FUTURE DIRECTIONS AND CONCLUSIONS

This case has demonstrated that a First Nation community in close proximity to a provincial border exhibits a high degree of cross-border and cross-jurisdictional mobility among its members, with varied temporal and spatial patterns. It has also suggested that current programming does not account for mobility clearly, and lack of clear inter-jurisdictional policies may be detrimental for mobile TB patients. In doing this, this research provides a window into understanding the impact of mobility on infectious diseases such as TB that continue to burden First Nations populations. While it also identifies ad hoc mechanisms for maintaining treatment across jurisdictions, it cannot speak to the actual implications on the ground. Neither has this been explored in the literature. Therefore, additional research is needed to understand mobility and its direct impact on TB transmission, care and prevention programming. Through this study, my goal was to understand the current state of TB programming and policy at both a regional and national level regarding First Nations on reserve. And comparing this to the impact of inter-jurisdictional mobility and I hope my findings and recommendations can help inform new policies to work towards the WHO's goal of eliminating TB by 2050.

I can draw the following conclusions from the present case study. I identified the major motivations, patterns, and frequency of mobility out of the community. Wintertime is the most common time to travel inter-provincially to AB because of ice roads, often for shopping, accessibility to necessities, and employment. Saskatoon is the most common destination out of the community for medical purposes, and shopping during the medical visits. CW and La Loche are closely related but exist in two different jurisdictions, both La Loche and Saskatoon are under provincial jurisdiction while CW is under federal jurisdiction. The decentralized healthcare system in Canada and the existence of competing jurisdictions makes it more difficult to maintain continuity in care, especially for mobile patients. Although obtaining definitive evidence that this patchwork system has resulted in limiting efforts at TB control was beyond the scope of this study, this remains a distinct possibility, as participants called for greater

coordination and communication between jurisdictions and ensuring continuity of care and treatment completion.

The knowledge I have gained from this research furthers our understanding of what is currently missing in policies for mobile patients. It also contributes to the growing literature on First Nations health and research on geographic mobility. Geographic location and mobility should be considered as a DOH to help inform health policy and programming, especially for border communities. The findings from this study offer a window into a phenomenon that requires further research in order to be understood, however it can help inform future policy, programming, and research paths. This study focused on a small region in Northern Saskatchewan, future studies can expand further to understand mobility on a larger scale. Future policies thus can be informed by understanding mobility patterns of different populations in Canada. First Nations are a highly mobile population and jurisdictional policies need to account for this.

As an emerging settler scholar, and a child of immigrant parents this research process has shaped and changed my worldview greatly Working alongside Indigenous communities and experts in the healthcare field has been an upward journey of learning. I had the privilege to learn decolonizing approaches to research and to unlearn much of what the western education system has taught me regarding Indigenous peoples of Canada. There is a strong sense of community and home amongst the people of CW rooted in kinship and support. Future steps in the eradication of TB must draw upon the inherent strengths of the community and must be guided by the voices of the community. Finally, my time in CW has taught me to appreciate my own culture and community greatly.

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APPENDIX A

Interview Questions for community participants

- What does home mean to you?
 - Where do you consider home?
- What role does mobility (or travel) play in your life?
 - Is mobility out of the community important to you?
- How often do you travel out of the community?
 - How long do you travel for?
 - Where do you travel to the most?
- What are the most common routes to Fort McMurray? (Edmonton, Janvier, etc)
 - Do these routes change with the seasons?
- What times of the year do you travel the most?
 - Do you think travel patterns change at different times?
- What are your main reasons for travelling out of the community?
 - (depending on the answers)
 - How important is travel for maintaining **familial** connections? (Garson Lake)
 - Are travel routes today still reflective of **traditional** hunting routes?
 - Why do you travel out of the community for **work**? How often do you have to travel for work? How often can you come back?
- What does TB mean to you?
 - If you feel comfortable sharing, what experiences have you had with TB?

APPENDIX B

Interview guide Healthcare Workers

- What is the standard procedure for patients presenting with symptoms of TB in (Location)?
 - To what extent is the TB standard outlined by your province followed by healthcare workers?
 - Is there a difference between TB programming (care and prevention) in rural compared to urban and city?
 - Where are sputum cultures sent if the patient is from a different jurisdiction?
- If an active TB patient from another province comes to your health location, what is the procedure?
 - If reported, which jurisdiction do you report “mobile” cases to? Is reporting to specific health branches required?
 - What is the inter jurisdictional procedure of reporting active cases for “Status Indian” First Nations?
 - If the patient is still completing their treatment and has travelled between jurisdictions, what are the steps that you take?
 - Can treatment be given in a different jurisdiction?
- Do you utilize DOT? What is the procedure for DOT?
 - What is the procedure for patient isolation? Home isolation?
 - Within the TB strategies, isolation and DOT procedures are different for Saskatchewan and Alberta, how do you think this may impact potentially mobile patients?
- What is the role of the “patient charter of rights” in your community regarding TB treatment?

Additional questions for NITHA and other policy workers

- What is NITHA’s role in TB among First Nations?
 - Is the role different for Métis populations?
- What do jurisdictional separation of health procedures mean for TB prevention and care?