

The Determinants of Tuberculosis Transmission in Indigenous People in Canada and New Zealand

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By

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ABSTRACT

The disparity in tuberculosis rates between Indigenous and non-Indigenous people persists in Canada and New Zealand. The most common form of tuberculosis in humans is pulmonary tuberculosis so eliminating tuberculosis transmission is an important obstacle to decreasing the overall rates of the disease. In both Canada and New Zealand, social determinants of health such as housing conditions, access to health care and historical influences (including similar experiences with colonization) have been implicated in the high rates of tuberculosis. This thesis examines and compares the social determinants of tuberculosis transmission among Aboriginal people in the Canadian province of Alberta and Maori and Pacific people in New Zealand.

In Alberta, ten Aboriginal individuals with smear-positive pulmonary tuberculosis participating in a larger prairie wide study were divided into two groups (transmitter and non-transmitter) based on transmission events identified through contact tracing and DNA fingerprinting. Interviews with the ten participants were analyzed and compared using an interpretive phenomenological perspective and informed by an Aboriginal framework of health. Survey data from the same individuals provided complementary descriptive statistics. In New Zealand, interviews with Maori and Pacific pulmonary TB participants that had been conducted as part of other studies were accessed and analyzed using an interpretive phenomenological perspective. Like in Canada, Indigenous frameworks of health specific to Maori and Pacific people informed the analysis.

The Canadian analysis identified three factors of greater relevance within the transmission group: substance use, patient-delay-in-seeking-treatment, and number of contacts. These factors were also relevant for the Maori and Pacific experience of tuberculosis. The results of this cross-cultural comparative study highlight the complexity of the experience of tuberculosis for Indigenous people in both Canada and New Zealand. Future research and education and intervention programs must not only consider the proximal social determinants of health, such as poverty, unemployment, etc, but also the more distal social determinants of health and the “causes of causes” such as colonization and its multi-generational effects.

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DEDICATION

I wish to dedicate this work to my parents.

To my father, the smartest person I have ever known. I wish I could have shared this journey with you. I miss you every day.

To my mother, the strongest person I have ever known. Your ability to give thanks, laugh, love, show patience, persevere, teach, learn and encourage every day is remarkable and inspiring.

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LIST OF TERMS

Aboriginal: In Canada, includes three distinct groups – North American Indians, Métis and Inuit. The term Aboriginal is used consistent with the Canadian Constitution which recognizes Aboriginal people as descendents of the original people of North America (Waldram, Herring & Young, 2006).

First Nation: Refers to those with Indian ‘status’ and those without. “‘Status’ or ‘registered’ Indians are those individuals legally recognized by the federal government to be ‘Indians’ for the purposes of the Indian Act”. The Indian Act was first passed in 1867 as a way of facilitating the administration of programs and facilitating the assimilation of ‘Indian’ people into mainstream Canadian society. Many people of Indian ancestry lost their ‘status’ for a variety of reasons (Waldram, Herring & Young, 2006).

Indigenous: People who are descendents of groups who were native to a land prior to the time when persons of a different culture, ethnic origin or geographical location arrived.

Inuit: The Inuit people are an Aboriginal people of Canada, distinct from other Aboriginal groups, who have traditionally inhabited the Northern Regions of the country (Waldram, Herring & Young, 2006).

Maori: the Indigenous people of New Zealand whose ancestors are Polynesian sailors (Oh, 2008; Belich, 1996).

Métis: Métis generally refers to people with mixed Indian-European ancestry as a result of intermarriage between European settlers and ‘Indians’ but who have been recognized by the Canadian government as a unique cultural group (Waldram, Herring & Young, 2006; Ballard et al., 2009).

Pacific islands: Islands in the Pacific Ocean. In this thesis, the Pacific people interviewed were from Tuvalu, Samoa and the Cook Islands, islands that are part of the Polynesian Pacific islands.

Pacific people: In this thesis, refers to people from the Pacific islands surrounding New Zealand who are living in New Zealand.

Pakeha: Maori word for the Non-Maori “white” European population in New Zealand.

Chapter One: Introduction

The disparity in tuberculosis rates between Indigenous people and non-Indigenous people persists in Canada and New Zealand. The most recent Public Health Agency of Canada (PHAC) data, reporting rates from 2009, indicate that the incidence of tuberculosis continues to be much greater in Aboriginal people (First Nation, Inuit and Métis) at 27.8 per 100,000 persons compared to a rate of 1.0 per 100,000 persons for Canadian-born non-Aboriginal people (PHAC, 2011). The rate ratio between Aboriginal people in Canada and Canadian-born non-Aboriginal people has increased over time (13.5 in 2002, 15.5 in 2005 and 27.8 in 2009) (PHAC, 2004; PHAC, 2008; PHAC, 2011). In New Zealand, disparity in tuberculosis rates exist between the Indigenous Maori people of New Zealand, Pacific people living in New Zealand and the Pakeha (non-Maori “white” European population). Between 1995 and 2004 the incidence rate of tuberculosis was 1.0 per 100,000 for New Zealand born Europeans, 10.5 per 100,000 persons for Maori people and 22.3 per 100,000 persons for Pacific people living in New Zealand (Das, Baker & Calder, 2006).

The most common form of disease, caused by *Mycobacterium tuberculosis*, is pulmonary tuberculosis. Within the lungs, the bacterium is taken up and if not contained by the immune system, is able to grow uncontrollably, resulting in the subsequent development of tuberculosis disease. The bacterium is propelled into the environment when a person with pulmonary disease coughs, speaks or sings and aerosolized droplets can then be inhaled by those who are in close contact with the infectious case (Menziés & Khan, 2007). Efforts to decrease the rates of tuberculosis must focus on controlling transmission as a means to reduce the overall burden of the disease. It has been observed that not all patients who have pulmonary tuberculosis transmit the disease, and thus in understanding tuberculosis transmission, research must include an examination of specific transmission events to highlight the factors that influence and result in transmission with or without the generation of secondary cases.

It is believed that the continued high burden of tuberculosis in Indigenous people has less to do with a biomedical understanding of the disease and treatment and more to do with the failure to understand the social conditions of the disease. The continued disparity in tuberculosis rates within Indigenous people highlights the importance of understanding the disease within social, cultural and historical contexts of these populations. In both Canada and New Zealand social determinants of health including poor housing conditions, unemployment, substance use

and negative health care experiences are implicated in contributing to the high disparity of disease (Clark, Riben & Nowgesic, 2002; De Zoysa & Shoemack, 2001; McElnay, Thornley & Armstrong, 2004; Reading & Wien, 2009).

1.1 Research Objectives

The overall objective of comparing the experience of tuberculosis within Canada and New Zealand is achieved by two context-specific research objectives and a number of related research questions.

1.1.1 Research Objective #1.

Compare the experience of tuberculosis between Alberta Aboriginal individuals who have been diagnosed with smear-positive pulmonary tuberculosis between January 1st 2007 and December 31st 2008 and have been linked to transmission events, to those diagnosed in the same time period who have not been linked to transmission events.

1.1.1.1 Research Question #1.

What are the differences in social conditions between Aboriginal individuals who are diagnosed with tuberculosis and linked with transmission and Aboriginal individuals diagnosed with tuberculosis in the same time period who have not been linked to transmission events?

1.1.2 Research Objective #2.

Explore the experience of tuberculosis for Maori and Pacific people in New Zealand and compare the relevant social determinants of health linked to transmission and non-transmission in the Aboriginal experience with tuberculosis.

1.1.2.1 Research Question #2.

What are the social conditions in which Maori and Pacific people experience tuberculosis in New Zealand?

1.2.2.2 Research Question #3.

How do the factors associated with the experience of tuberculosis for Maori and Pacific people in New Zealand compare to the factors associated with tuberculosis transmission for Aboriginal people in Alberta?

1.2 Methods and Results

In Canada, the project accessed qualitative and quantitative information of ten Aboriginal people from Alberta all with smear-positive pulmonary tuberculosis. The ten participants were divided into two groups based on their transmission activity (transmitter and non-transmitter groups) and compared for unique and comparable factors within their experience with tuberculosis as a means of identifying specific social determinants operating in a series of proven transmission events. In New Zealand, the project accessed qualitative interview data of Maori and Pacific TB patients (and family members). The analysis evaluated the experience of tuberculosis for the Indigenous people in New Zealand and compared the social factors relevant in the New Zealand Indigenous experience of tuberculosis with the factors identified as being associated with increased transmission for Aboriginal people in Canada.

The results of the study identified three factors of greater relevance for Canadian Aboriginal TB participants in the transmitter group. These factors are also significant in the Maori and Pacific people's experience with tuberculosis in New Zealand. In the discussion, these factors are explored in relation to one another and as potential mechanisms of increasing transmission. Additionally, these factors are discussed in relation to other social determinants of health that may also affect tuberculosis and transmission rates. In placing these results within the Indigenous frameworks of health that informed the analysis of the study in both Canada and New Zealand, the importance of recognizing both proximal social determinants of health, such as poverty, substance use, etc as well as identifying the "causes of causes" such as colonization and its multi-generational effects are discussed. The discussion is also informed by other literature on social determinants of health for Aboriginal people in Canada and Maori and Pacific people in New Zealand.

1.3 The Researcher

My initial interest in being involved in a study looking at the relationship between health and culture stemmed from undergraduate education in Biology. I was interested in the literature around genetics and different cultural groups and different biological adaptations in response to geography, environment and behaviour. My thesis and involvement in the larger research projects in both Canada and New Zealand has fuelled my continued enthusiasm for the

relationship between culture, history, health and health-seeking behaviours. Additionally, it has allowed me to reflect on my up-bringing and experiences as a non-Indigenous person living within a city with a large Indigenous population.

1.4 Organization of Thesis

This thesis is divided into six chapters. Chapter one introduces the topic and outlines the research questions and objectives used to guide the analysis, results and discussion. Chapter two and three are the literature review of the contextual information that relates to the objectives of this thesis. Chapter two, tuberculosis, introduces tuberculosis as a disease and discusses characteristics of transmission and rates of tuberculosis in both Canada and New Zealand. Chapter 3, tuberculosis and Indigenous people, provides background information related to the history of tuberculosis within Canada and New Zealand and introduces population-specific frameworks of health that guided the analysis. Chapter four, methodology, outlines the data collection and analysis that occurred in both Canada and New Zealand and chapter five presents the results of such analysis. Finally, chapter six offers a discussion of the results focusing on the social determinants of health relevant to tuberculosis in both contexts. Chapter six also includes a discussion on the strengths and limitations of the project and concludes with an overview of the project and implications for future research.

Chapter Two: Tuberculosis

The literature review was developed as a means of describing the current knowledge of tuberculosis within the two countries, Canada and New Zealand, in which this research is located. It is divided into two chapters. This chapter describes tuberculosis as a disease, rates of the disease in Canada and New Zealand and characteristics associated with tuberculosis transmission. The second chapter of the literature review, chapter three, looks at the history and demographics of the Indigenous people of Canada and New Zealand and discusses the relevance of tuberculosis. The purpose of the literature review is to highlight the research that has occurred and describe the relevant contextual information for the research.

2.1 Tuberculosis

In humans, the primary cause of tuberculosis is the bacillus *Mycobacterium tuberculosis*, a genus of Actinobacteria. *M. tuberculosis* is a non-motile bacillus that grows slowly and, under optimal conditions, reproduces every twenty-four to forty-eight hours (Moulding, 1988). It is an aerobic bacterium requiring high levels of oxygen for growth. It is neither gram- positive nor – negative as the waxy coating on the cell surface makes the bacillus impermeable to gram staining (Moulding, 1988). *M. tuberculosis* was identified in 1882 by Robert Koch (Moulding, 1988) and the genome was sequenced in 1998 (Cole, et al., 2002). *M. tuberculosis* (including *M.tuberculosis subsp. Canetti*), as well as *M. bovis*, *M. bovis* BCG, *M. africanum*, *M. caprae*, *M. microti* and *M. pinnipedii* are a genetically related group that make up the *Mycobacterium tuberculosis complex* and are all, with the exception of *M. bovis* BCG, included in the Canadian case definition of tuberculosis (Daschuk, Hackett & MacNeil, 2010; Wolfe, Antonation, & Sharma, 2007).

The most common form of tuberculosis in humans is pulmonary tuberculosis: infection of the respiratory tract (accounting for 68% of all TB cases in 2009 in Canada) (Public Health Agency of Canada [PHAC], 2011). Infection is acquired through inhalation of the bacterium. In the past, infection with *M. bovis* was common due to ingestion of unpasteurized milk. This infection is much less prevalent today, although immigrants from areas where pasteurization of dairy products is not as regulated may be infected with this species. Additionally, the organism may occasionally be isolated from older individuals who acquired the infection before milk-control was common (Long & Schwartzman, 2007). Tuberculosis can also involve non-

respiratory sites, occurring in the peripheral lymphatic system, bones and joints, genitourinary system, gastro-intestinal tract, central nervous system, ocular system and pericardium (Cook & Long, 2007). Non-respiratory tuberculosis disease does not contribute significantly to the rates of tuberculosis transmission however, control of these disease forms is important as transmission may occur if aerosolization of the bacterium occurs during surgical procedures or post-mortem examination (Cook & Long, 2007).

Transmission of the bacterium occurs most commonly through bacterium-infected droplets of moisture expelled in the environment by a respiratory case. For most people who become infected by *M. tuberculosis* and develop primary infection, progression to tuberculosis disease does not occur. In approximately 95% of immunocompetent individuals the immune system is able to effectively contain the primary infection resulting in a latent infection, but no immediate development of disease (figure 2.1, p.7) (Gryzbowski, 1983; Long & Schwartzmann, 2007). The latent infection may persist in the host individual for years with no display of symptoms or experience of adverse effects. In 5% of these people, the latent infection may be reactivated years later as post-primary TB disease, often occurring due to co-morbidity (Flynn, 2006) or sociocultural stresses (Daschuk, Hackett & MacNeil, 2006). In the approximately 5% of immunocompetent individuals whose immune system is not able to contain the infection, primary disease will develop. The probability of developing primary disease after infection is also much greater in immunocompromised individuals (Long & Schwartzmann, 2007). An individual with Acquired Immune Deficiency Syndrome (AIDS) has a 110-170 times greater risk of developing TB than a person with no known risk factors and an individual with Human Immunologic Virus (HIV) has a greater risk of 50-110 times than a person with no known risk factors (Menzies & Khan, 2007). Immunologic containment by an individual's immune system is deficient in individuals with HIV (Houston et al., 2007). Globally, TB is the most common cause-of-death in HIV infected individuals (Houston et al., 2007).

The immune response to the infection is complex and involves both the innate and adaptive immune system (Flynn, 2006). If the organism is successful in reaching the lungs it will begin multiplying within the alveolar macrophages (Flynn, 2006; Long & Schwartzmann, 2007). If the innate response is unable to destroy the bacterium, cell-mediated immunity and delayed-type hypersensitivity immunity are activated (Long & Schwartzmann, 2007). The subsequent

adaptive immune responses include activation of the CD4⁺ and CD8⁺ T cells (Flynn, 2006). The inflammatory response includes the formation of granulomas by the host immune system that work to limit the spread of infection. In the majority of infected individuals, the infection is contained and tuberculosis disease does not develop (Long & Schwartzmann, 2007).

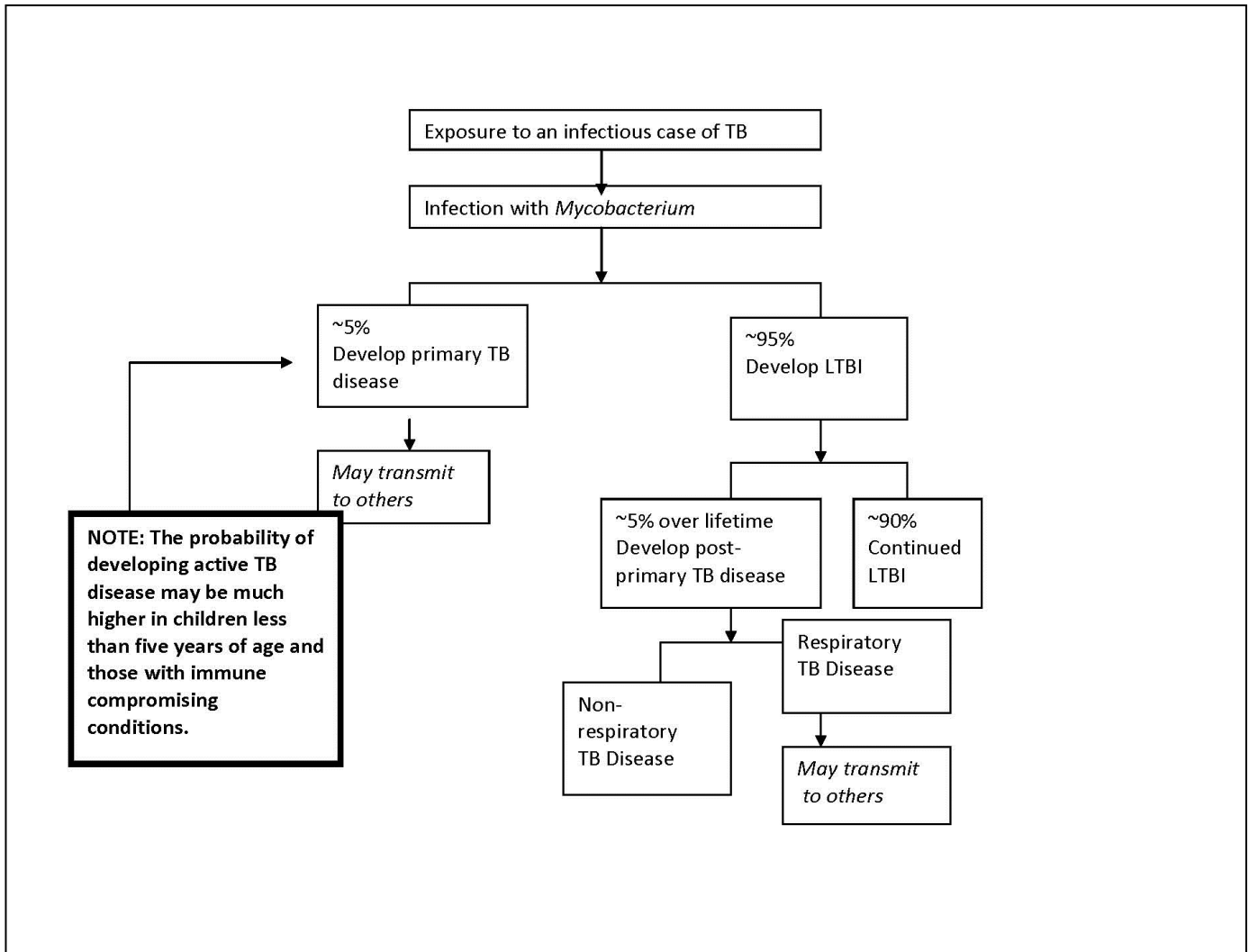


Figure 2.1: The pathogenesis of *Mycobacterium tuberculosis* in infected people. (Adapted from Alberta Health and Wellness [AHW], 2010).

Immunocompromised individuals may be deficient in granuloma formation and thus are not efficient at containing the infection. Without the formation of granulomas to control the bacteria, the infection cannot be contained (Flynn, 2006). In children, primary pulmonary tuberculosis refers to disease in the lung parenchyma or draining lymph node, while in adults and adolescents primary tuberculosis refers to tuberculosis pleurisy. For both, the development of the

primary disease generally occurs within eighteen to twenty-four months after infection. It is important to note that the process outlined in figure 2.1 (p.7) as to the pathogenesis of *M. tuberculosis* in people who have become infected after exposure is a generalization; it does not always apply and there are factors that may affect the process (Long & Schwartzmann, 2007). Age and sex have been found to affect resistance and development as mortality and morbidity are greater in infants, females in younger age groups and males at older ages, although the reasons for these differences are not completely understood. Additionally poor nutrition and host genetic factors are believed to affect individual susceptibility to tuberculosis (Long & Schwartzmann, 2007).

The classic symptom of active tuberculosis disease is a cough lasting at least three weeks (Menzies & Khan, 2007). Additional symptoms include fever and night sweats, although these may be absent in the very young or elderly (AHW, 2010). Hemoptysis, anorexia, weight loss and chest pain are symptoms that often indicate more advanced disease (Menzies & Khan, 2007).

2.2 Tuberculosis Diagnosis and Health Care Services

The following section outlines the guidelines for diagnosis of TB disease and identifies the TB associated health care services in Canada and New Zealand.

2.2.1 Tuberculosis Diagnosis.

The primary test for diagnosing tuberculosis infection is the tuberculin skin test (TST). This test involves an intradermal injection of a small amount of protein from the *M. tuberculosis* bacterium (Menzies & Khan, 2007). If an individual has cell-mediated immunity to the antigens, a hypersensitivity reaction will occur within forty-eight to seventy-two hours (Menzies & Khan, 2007). The Mantoux test is the most popular, accurate, reliable and consistent TST (Menzies & Khan, 2007).

Declaring a positive TST should be based on three factors: (1) size of TST reaction, (2) positive predictive value and (3) risk of disease if infection is truly present. Table 2.1 (p.9) outlines a guideline for interpreting TST results based on size (Menzies & Khan, 2007).

Table 2.1: The First Dimension of Interpretation of the TST – Size (Menzies & Khan, 2007)

TST Reaction Size (mm induration ¹)	Situation in which reaction is considered positive
0 – 4	HIV infection with immune suppression AND the expected likelihood of TB infection is high (e.g. patient is from a population with a high prevalence of TB infection, is a close contact of an active contagious case, or has an abnormal x-ray).
5 – 9	HIV Infection Close contact of active infection Children suspected of having tuberculosis disease Abnormal chest x-ray with fibronodular disease Other immune suppression
≥ 10	All others

The positive predictive value of the TST is the probability that a positive test result represents the true presence of TB infection (Menzies & Khan, 2007). The positive predictive value will be low in populations at low risk of TB infection, with previous exposure to nontuberculous mycobacteria or previous BCG vaccination (Menzies & Khan, 2007). The third factor to consider when interpreting the TST is the risk of disease in the individual if the infection is present. Risk factors for a *high* likelihood of developing active TB from infection of *M. tuberculosis* include co-morbidities such as AIDS, HIV, chronic renal failure and carcinoma of head and neck, transplantation, recent TB infection, and abnormal chest x-ray indicating fibronodular disease (Menzies & Khan, 2007). Factors related to an *increased* risk of developing active disease include diabetes mellitus, being underweight, cigarette smoking and young age (Menzies & Khan, 2007).

¹ Palpable, raised, hardened area or swelling (Centers for Disease Control and Prevention)

If an individual is determined to have a positive TST further medical evaluations are necessary to conclude a TB disease diagnosis and these include assessment of symptoms and risk factors, medical history and chest radiography. Additionally, sputum for acid-fast bacteria smear and culture should be taken if symptoms are present or the chest x-ray is abnormal (Menzies & Khan, 2007). A chest x-ray of a typical pulmonary TB case will include the following:

1. Apical-posterior segments of upper lobes or superior segment of lower lobes in 90%.
2. Volume loss as a result of the destructive and fibrotic nature of TB.
3. Cavitation.

Mycobacterial culture and examination of smears of sputum are two important processes in the evaluation of pulmonary TB. Examination of sputum is a rapid test and the most widely used while mycobacterial cultures are considered to be the gold standard in pulmonary TB diagnosis (Menzies & Khan, 2007).

It is recommended that three sputum samples are collected eight to twenty-four hours apart. For detection, sputum specimens must be homogenized² and concentrated³. The threshold of detection of the bacterium in concentrated specimens is 5,000 – 10,000 bacteria/mL of sputum (Menzies & Khan, 2007). In contrast, the threshold of bacterium detected by culture is 10-100 bacteria. The sensitivity of culture testing is much greater than smear testing. However, an individual who is culture positive and smear positive is considered more infectious than an individual who is culture positive but smear negative as the smear positive is indicative of a greater number of bacterium and therefore a greater potential for transmission (Long & Schwartzmann, 2007).

2.2.2 Tuberculosis Services in Canada.

In Canada, TB control is organized into two different models in the Provinces and Territories. The Provinces involved in the Determinants of Tuberculosis Transmission Project (Alberta, Saskatchewan and Manitoba) are organized based on a centralized control program, which grew out of the sanatorium system (Stirling & Enarson, 2007). All three levels of government are involved. Every province in Canada has legislation requiring the reporting of TB cases (Stirling & Enarson, 2007). Additionally, Public Health legislation bestows power to

² To eliminate the variety of other microorganisms contained within specimens submitted for sampling (Pfyffer, 2003).

³ To maximize the potential yield of mycobacterium (Pfyffer, 2003).

public health authorities to ensure that all peoples with a suspected or confirmed case of TB receive diagnosis and treatment (Stirling & Enarson, 2007). TB control in each province includes health care professionals involved in aspects of TB care including diagnosis and treatment, case reporting, contact tracing, and follow-up, which are all areas crucial to identifying TB cases, ensuring timely diagnosis and treatment, and limiting transmission.

In Alberta, the province where all ten TB cases for this thesis were diagnosed, treated and subsequently interviewed, the management of TB and latent TB infection is centralized out of Alberta Health Services (AHS) [prior to April 1, 2010 centralization occurred through Alberta Health and Wellness] (AHW, 2010). There are three dedicated public health TB clinics, one free-standing clinic in each of Calgary and Edmonton, and a provincial (virtual) clinic in Edmonton that serves rural Alberta, including reserve communities. The clinic that TB cases will be referred to is meant to be based on their residence. Those residing outside the two central locations of Calgary and Edmonton are followed through by the AHS provincial TB services located in Edmonton (AHW, 2010). Referrals to the TB clinics are made by either a physician or public health nurse. Alberta Health Services is financially responsible for TB patients who do not have health care coverage (AHW, 2010). In Alberta, all treatment of TB is directly observed therapy (DOT), “ the process whereby a health care worker or pill dispenser watches the patient swallow each dose of medication, helping to ensure that higher treatment completion rates are achieved” (Hoeppner, Ward & Elwood, 2007). All TB prevention control is administered by a public health nursing network, with clinical expertise provided by university-based pulmonary and infectious disease physicians (AHW, 2010).

Each TB patient has one or more public health nurse managers who communicate directly with the patient and take direction from TB control physicians (AHW, 2010). Local public health and the TB clinics are legally responsible to conduct contact tracing and ensure the completeness of such activities. Contact tracing includes identifying and evaluating contacts of diagnosed TB disease cases, providing treatment to contacts found to have TB disease, offering treatment to those contacts found to have latent TB infection, monitoring adherence to prescribed treatment, and ensuring a system is in place to assess completion of treatment (AHW, 2010).

After early detection of cases, the second priority of TB control programs is the early detection of potential infected contacts of diagnosed individuals and the initiation of preventative or curative treatment (Tannenbaum, Yuan & Wallington, 2007). All close contacts identified

during contact tracing should be interviewed regarding their relationship with the source case and their recent symptoms and activities. If deemed appropriate, further investigation into whether a person has active TB should occur (Tannenbaum, Yuan & Wellington, 2007). In relation to transmission, a secondary case is an individual who through contact tracing, is deemed to have active TB and can be linked with the source case through relationship tracing. Secondary cases are also confirmed through DNA fingerprinting if the fingerprint of the *M. tuberculosis* isolate of the source case is identical to the *M. tuberculosis* isolate of the contact-in-question, and the two individuals can be linked through relationship tracing (figure 2.2, p.13).

If a contact is determined not to have active TB, and is thus not a secondary case of the source case, exposed contacts should still receive a tuberculin skin test (TST), unless there is a history of TB treatment or a prior positive TST (Tannenbaum, Yuan & Wellington, 2007). In interpreting the TST results, if the contact does not have a documented previous TST and the current TST result is $\geq 5 \text{ mm}^4$ (on the first test or on the test at least eight weeks after the last exposure) the individual is considered to be positive for tuberculosis infection (figure 2.2, p.13). In relationship to transmission this individual is considered to be a recent positive. If the contact-in-question does have a documented previous TST result that was negative ($<5\text{mm}$), their test is considered to be positive if the TST result is $\geq 10 \text{ mm}^4$ (on the first test or on the test at least eight weeks after the last exposure) and this contact is considered to be a tuberculin converter (figure 2.2, p.13) (Menzies & Khan, 2007).

⁴ Of induration (palpable, raised, hardened area or swelling) (Centers for Disease Control and Prevention)

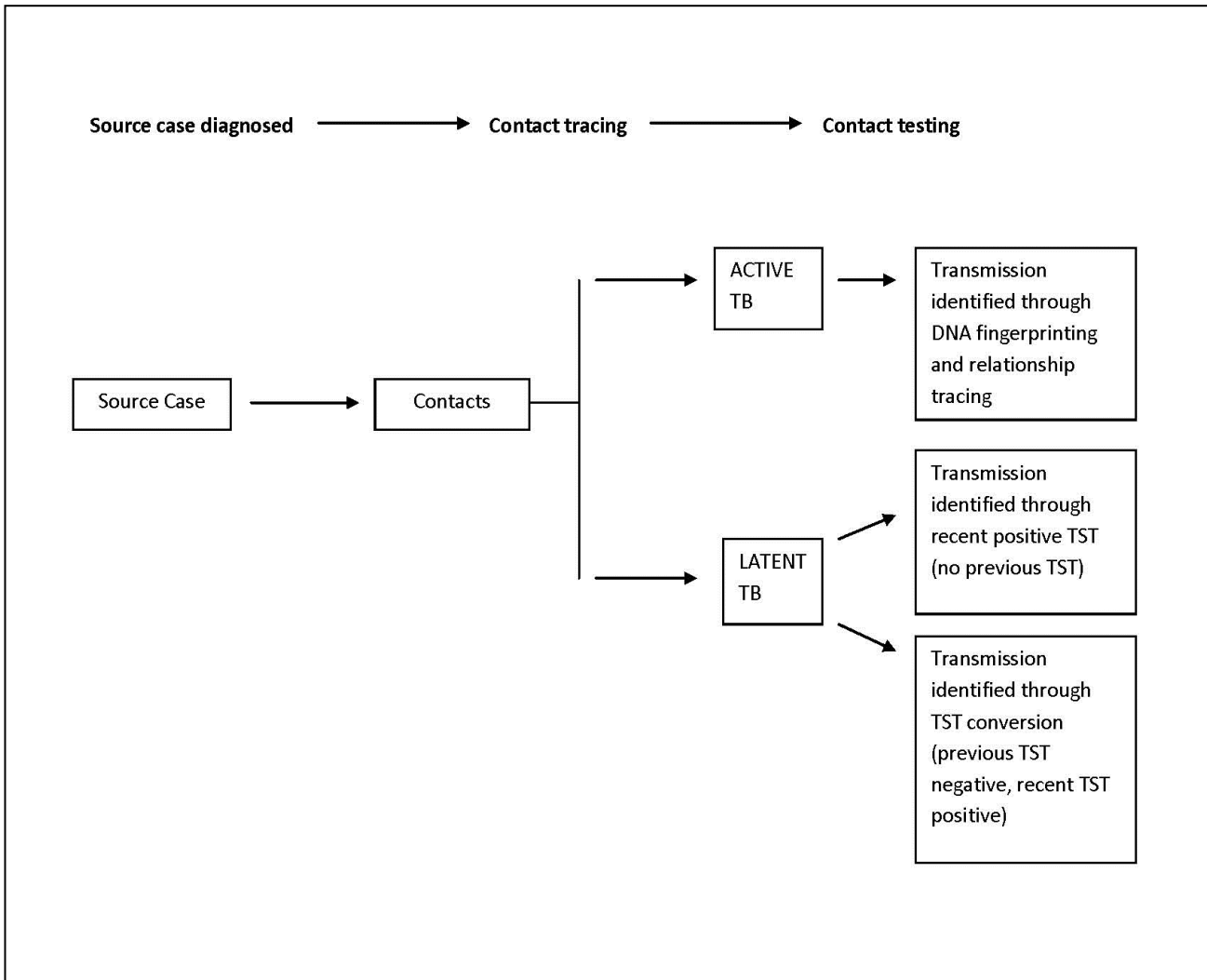


Figure 2.2: Process for contact tracing and identification of transmission events.

2.2.3 Tuberculosis Services in New Zealand.

In New Zealand, the majority of TB cases are identified through patient presentation to a general physician or other clinician (Calder, Gao & Simmons, 2003), through public health contact screening and through immigration screening (Harrison, 2003). Any physician suspecting or diagnosing TB is legally required to contact Public Health Services (Turnbull, 2003). In Auckland, all pulmonary TB cases are referred to tertiary services at one of two hospitals that deal with TB cases, while extra-pulmonary cases may be managed by secondary services (Hay, 2010). Once the Public Health Services (PHS) has been notified of a new TB case, the PHS becomes involved in on-going community care and liaison with clinical services. The Auckland Regional Public Health Services (ARPHS) serves three district health boards covering seven different district councils (Hay, 2010). Similar to Canada, the Medical Officer of Health (MoH)

has the legal power to require people suspected of having TB to attend appointments. As a result, because people are required-by-law to attend appointments and take their prescribed treatment, all necessary investigation and treatment is free-of-charge to patients, apart from the initial visit to the GP. This is especially notable in that people, who are not legal residents of New Zealand and thus are not entitled to partake or benefit in the health-care system, are able to receive free TB treatment if they are diagnosed with TB while in the country (Pikholz, 2008).

The Public Health Nurse (PHN) has an important role in the ARPHS TB services. The PHN is often the first person to visit the patient upon diagnosis where they explain the available services and the potential progression of events. The PHN will provide feedback to the clinician as to how likely they believe the patient is to adhere to treatment regimes. Once released from hospital, the PHN conducts regular visits with the patient to monitor treatment adherence and administer directly-observed-therapy (DOT) (Hay, 2010). The PHN-patient relationship is very important in TB education and health promotion. The PHN is able to provide transport for patients to get to medical appointments and can apply for financial help on behalf of the patient from Lung Health Auckland.

Contact tracing is an important step in controlling tuberculosis transmission, and in Auckland is the responsibility of the ARPHS. They are required to follow-up on contacts of infectious TB patients and provide information to the contacts on testing and potential treatments options (Hay, 2010).

2.3 Tuberculosis Transmission

As figure 2.1 shows (p.7), people who develop TB disease are able to potentially transmit to others and therefore elimination of disease transmission is an important obstacle in decreasing disease incidence. The objective of this research project is to understand why, in a cohort of individuals all with smear positive tuberculosis, some transmit the disease, while others do not. The focus in this thesis is on social determinants of increased transmission events – what are the circumstances under which increased transmission events occur? The following section of the chapter discusses characteristics associated with tuberculosis transmission. It briefly explores relevant individual characteristics, including a brief description of some related genetic research, environmental factors and social determinants of health. A more detailed and population-specific discussion of social determinants of tuberculosis is in chapter three.

As previously mentioned, in both Canada and New Zealand, contact tracing occurs by public health services in which contacts of recently diagnosed TB cases are identified and investigated for their own TB infection. The usual transmission event is one in which a contact of a known TB disease case is determined to be newly infected (determined through a TST), is a tuberculin converter (an individual's most recent TST is positive while their previous TST was negative) or is a secondary case, and their initial isolate and the isolate from the source case are determined to have an identical DNA fingerprint. A transmission cluster is two-or-more individuals who have the same strain of *M. tuberculosis*, confirmed by DNA fingerprinting, and have a conventional epidemiological link to one another.

Transmission depends on several factors. Aerosolized bacteria-containing droplets from an infectious case have a slow settling rate so can persist in the surrounding environment and/or can be transported through air currents to other places (Long & Schwartzmann, 2007). The droplets cannot be filtered out through surgical masks or inhibited by an individual covering their mouth. Large expelled particles settle quickly and are rarely inhaled. If they do happen to be inhaled they are trapped in the upper airway; if they reach the trachea they are swept back into the larynx and then swallowed and do not generally cause infection. Only small droplets are able to reach the alveolar spaces and thus potentially cause infection. As small droplets can persist in the air, individuals in contact with the source case and within the contaminated environment have the potential to become infected. Droplets that settle on material within the environment are usually quickly destroyed through drying, heating and sunlight and thus do not generally cause infection (Long & Schwartzmann, 2007).

The ability of an infected individual to transmit the bacterium can depend on several factors. Smear positive patients usually have 5,000 or more bacteria per milliliter of sputum and are considered to be five times more infectious than smear-negative culture-positive patients (Long & Schwartzmann, 2007). The physical and chemical properties of a patient's sputum may determine their potential to aerosolize bacteria and in turn the potential for transmission. Aerosolization may depend upon the frequency, force, and region of the cough. For successful transmission to occur, a TB patient must be able to produce an airborne infectious droplet. Thus, transmission is generally limited to adolescent or adult patients as the force of a young child's cough is generally not great enough to produce an airborne droplet (Long & Schwartzmann, 2007).

The rate of transmission of tuberculosis is also influenced by the susceptibility of individuals who may potentially inhale the bacterium. In immunocompetent persons, prior infection to *M. tuberculosis* may provide some, but not complete protection. An individual's immune status may affect their vulnerability to tuberculosis disease, if infected. Individual genetic susceptibility has been studied extensively in different ethnic populations in relation to disease vulnerability (Yim & Selvaraj, 2010). Several important polymorphisms in candidate genes including human leukocyte antigen (HLA) alleles and other non-major histocompatibility complex genes have been associated with tuberculosis susceptibility (Yim & Selvaraj, 2010). These polymorphisms may provide genetic markers to predict an individual's vulnerability to the development of tuberculosis. Work on genetic variability in relation to tuberculosis by Larcombe et al (2005) noted that immunological adaptations, specifically different forms of T-cell immune responses, in addition to socioeconomic factors may influence susceptibility to tuberculosis (Larcombe et al., 2005). Additionally, there are a number of characteristics and conditions identified as being associated with a higher risk of TB infection in Canada. Table 2.2 (p.16) presents some conditions associated with a higher risk of TB infection in Canada (Long, Njoo & Hershfield, 1999). The mechanisms or pathways related to these descriptors can be considered through applying a population health – social determinants of health framework.

Table 2.2: Characteristics/conditions associated with higher risk of TB infection in Canada.

Country of origin with higher prevalence of TB
Aboriginal background
Homelessness
Substance abuse
Time spent in a correctional facility
Contact with a person who has TB
Older age
Health care occupation
Other occupational contact with high prevalence group

2.4 Social Determinants of Health

As previously mentioned, this thesis focuses on social components of increased tuberculosis transmission and is therefore situated in a population health framework. This section introduces a general population health framework in relation to TB and TB transmission. However, because this thesis considers the TB experience of Indigenous people, a secondary framework is necessary. Population specific frameworks related to health are introduced in the next chapter.

Social determinants of health affect components of the tuberculosis experience including the development of infection or disease (getting sick), and accessing health care, and completing treatment (factors associated with transmission of the disease). Figure 2.3 (p. 17) outlines a framework describing social determinants of health included in the World Health Organization's *Commission on Social Determinant's of Health Final Report* (Commission on Social Determinants of Health [CSDH, 2008]). It outlines several factors that have been recognized as influencing health outcomes including those associated with socioeconomic and political contexts, social positions, biological factors, psychosocial factors and the consideration of health care systems.

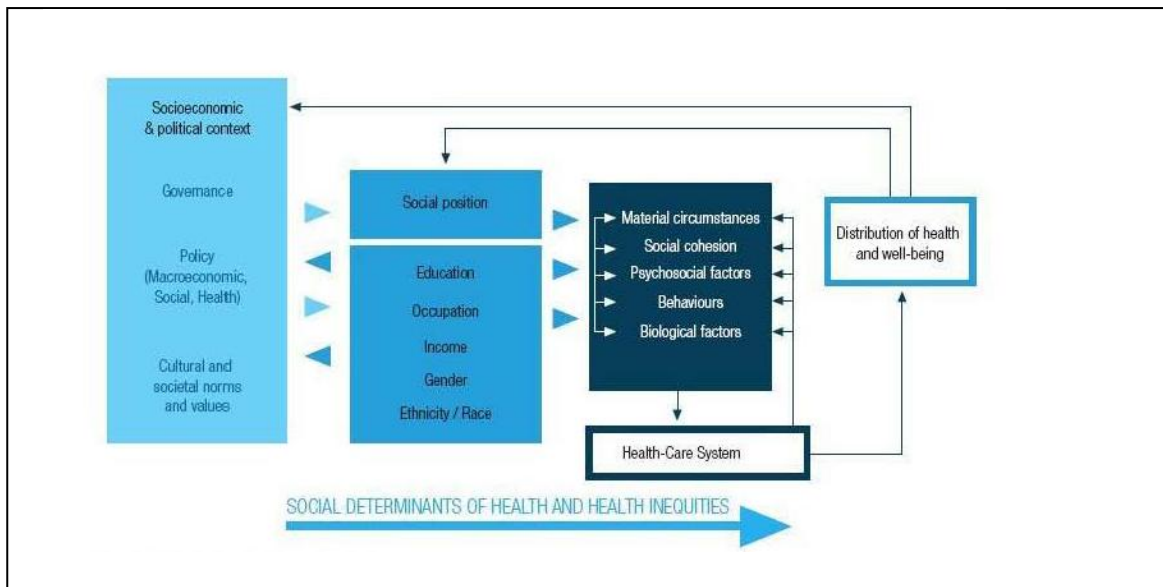


Figure 2.3: Social determinants of health and inequities (CSDH, 2008).

2.4.1 Social Determinants of Health and Tuberculosis.

Throughout the 20th century, rates of TB decreased in previously high-incident industrialized countries, due to rapid economic growth, social reform, poverty reduction and improved living conditions (Lonnroth et al., 2009). TB burden follows a socio-economic gradient, and thus poverty, and its related conditions, is a strong social determinant of TB (Lonnroth et al., 2009). Extensive research into the relationship between poverty and increased TB exists (Holtgrave & Crosby, 2004; Lopez De Fede et al., 2008; Marmot, 2005).

Often associated with poverty, housing conditions are closely related to tuberculosis transmission. As the bacterium can persist in the environment, the lack of air circulation and ventilation are important factors in transmission. The volume of air into which the bacteria are expelled determines the probability that a susceptible person will become infected (Long & Schwartzmann, 2007). Adequate ventilation dilutes the concentration of bacteria containing air droplets and thus decreases the potential for an individual to inhale bacterium and become infected. Proximity to the source case affects the potential of a susceptible person becoming infected with the bacterium (Long & Schwartzman, 2007). Dense living and poor air quality due to inadequate ventilation, and the presence of mold and smoke, contribute to poor air quality and poor respiratory health and are associated with increased risk of spread of TB (Baker, Venugopal & Howden-Chapman, 2008; Canadian Tuberculosis Committee, 2007; Wanyeki et al., 2006).

As TB infection is transmitted through bacteria propelled into the air through coughing and other mechanisms of force, medical treatment that reduces cough and kills or inhibits the bacterium is crucial to reducing the transmission potential (Golub et al., 2005; Long & Schwartzmann, 2007). Time-of-diagnosis and initiation of effective treatment are important factors in understanding transmission patterns and potential. Several American studies and investigations of TB outbreaks have found that delayed diagnosis is associated with greater transmission of infection to contacts (Golub et al., 2005; Golub et al., 2006; Mathur et al., 1994; Phillips, Charlie & Smith, 2004). This thesis investigates the relationship between social determinants of health and these tuberculosis-related factors, delayed diagnosis and initiation of treatment, as a means of exploring factors relevant to individuals at risk of TB disease and transmission that may act as barriers to seeking, accessing and receiving a TB diagnosis and treatment. Specifically, two high risk populations whose experiences with TB are explored in this thesis are Aboriginal people from Canada and Indigenous people from New Zealand.

2.5 Tuberculosis Rates

In both Canada and New Zealand, a disparity in the rates of TB between Indigenous and non-Indigenous people exists. This section of chapter two describes the contemporary rates of TB globally and in both Canada and New Zealand. A more in-depth examination of rates and history of TB in Indigenous people occurs in the next chapter.

The World Health Organization estimates the 2009 global incidence rate of TB to be 134 cases per 100,000 persons (World Health Organization (WHO), 2010). Also in 2009, an estimated 1.7 million people died as a result of TB. The countries with the highest incidence of TB in 2009 included India, China, Nigeria, Bangladesh and Pakistan (WHO, 2010).

2.5.1 Tuberculosis Rates in Canada.

In Canada, the provisional rate of TB in 2009 was 4.7 per 100,000 persons, with a total of 1599 new and reactivated cases (PHAC, 2011). The 2009 rate in Aboriginal people was 27.8 per 100,000 persons with 342 cases (PHAC, 2011). The majority of cases (67%) occurred in North American Indians. There were 89 cases in the Inuit people in 2009 and 25 in the Métis people (PHAC, 2011). The rate of TB in Canadian-born non-Aboriginal people was 1.0 per 100,000 persons for a total Canadian-born rate of 2.2 per 100,000 persons (PHAC, 2011). The rate of TB in 2009 for foreign-born people was 13.3 per 100,000 (PHAC, 2011).

In 2002, the rate for Canadian-born non-Aboriginal people was 2.6 per 100,000 persons (PHAC, 2004) and the rate for Canadian Aboriginal people was 35.0 per 100,000 persons. In 2005 the rate for Aboriginal people was 29.4 per 100,000 persons and for Canadian-born non-Aboriginal people was 1.9 per 100,000 (PHAC, 2008). The disparity between the two groups has increased over time (figure 2.4, p.20). In 2002, the rate ratio (the rate of disease in Aboriginal people compared to the rate in Canadian-born non-Aboriginal people) was 13.5, in 2005 the rate ratio was 15.5 and the rate ratio based on the 2009 provisional rates is 27.8.

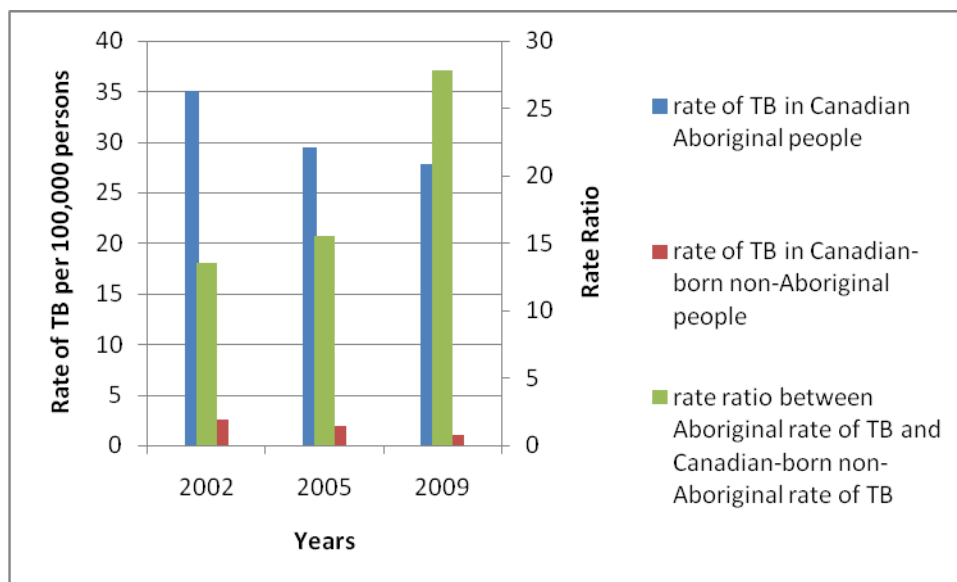


Figure 2.4: Rates of TB in Canadian Aboriginal people and Canadian-born non-Aboriginal people in 2002, 2005 and 2009 and rate ratios (data from PHAC 2004, PHAC, 2008 and PHAC, 2011).

2.5.2 Tuberculosis Rates in New Zealand.

Throughout the late 19th Century, tuberculosis was prevalent in both the Maori and the Pakeha (Maori word for non-Maori, “white” European) population. The Pakeha experienced a decrease in tuberculosis rates in the late 19th Century that the Maori did not experience. In 1942 in New Zealand, tuberculosis mortality in Maori was 422 per 100,000 compared to 39 per 100,000 in the non-Maori (Park, 2010).

Tuberculosis spread to the Pacific islands from Europe during the European empire expansion and colonization (Bates & Stead, 1993). In the Pacific islands, tuberculosis was a major problem in many areas until the mid and late 20th Century. In the Pacific islands themselves, the rates of tuberculosis differ significantly amongst the different nations (Park, 2010; Resture, 2010).

The 2009 rates of tuberculosis in New Zealand were 1.5 per 100,000 persons in the Pakeha population, 9.4 per 100,000 persons in the Maori population and 14.4 per 100,000 persons in the Pacific population (living in New Zealand) (Lopez, Sexton & Heffernan, 2010). Although these vary slightly from year to year based on the occurrence of TB outbreaks, the disparity between the rates of TB in Maori and Pacific people and New Zealand-born non-Indigenous people persists (Lopez, Sexton & Heffernan, 2010). Between 2003 and 2007, the

average annual rate of TB was 8.1 per 100,000 persons (Sexton, Perera & Pandey, 2008). The rate of tuberculosis disease within the Pacific people living in New Zealand during this time period was 26.2 per 100,000 persons and for the Maori people was 10.4 per 100,000 persons (Sexton, Perera & Pandey, 2008). The TB incidence rates by ethnicity between 1995 and 2004 in New Zealand were 2 per 100,000 for New Zealand born Europeans, 21.1 per 100,000 for Maori and 44.8 per 100,000 for Pacific people living in New Zealand (Das, Baker & Calder, 2006).

2.6 Summary

This chapter provided a background on TB in human populations. It examined characteristics of the bacterium, infection and disease, symptoms, diagnosis, and transmission. Understanding the determinants of transmission is a crucial component of reducing disease incidence. A population health/social determinants of health framework was introduced as an approach to addressing this challenge. Two high incidence populations in Canada and New Zealand were introduced. Chapter three presents a review of tuberculosis within Indigenous people in both Canada and New Zealand and introduces population-specific social determinants of health frameworks.

Chapter Three: Tuberculosis and Indigenous People

The objective of my thesis project is to examine and compare the social determinants of tuberculosis transmission in Indigenous people in Canada and New Zealand. Both population groups experience disproportionately high rates of TB compared to other populations in their respective countries. The previous chapter discussed characteristics of tuberculosis and social determinants of health associated with TB. This chapter begins with a description of the three Indigenous groups whose experiences with TB were explored in this thesis and then examines social determinants of health from an Indigenous perspective. The chapter concludes with the presentation of the Indigenous frameworks of health that were integrated with the more generic population health framework presented in chapter two.

3.1 Canadian Aboriginal People

Aboriginal people in Canada include three distinct groups – North American Indian, Métis, and Inuit. The term Aboriginal is used consistent with the Canadian Constitution which recognizes Aboriginal people as descendants of the original people of North America (Waldram, Herring & Young, 2006). The term First Nation refers to those with Indian status and those without (Waldram, Herring & Young, 2006). Métis generally refers to people with mixed Indian-European ancestry as a result of intermarriage between European settlers and ‘Indians’ but who have also been recognized by the Canadian government as a unique cultural group (Waldram, Herring & Young, 2006; Ballard et al., 2009). The Inuit people are an Aboriginal people of Canada, distinct from other Aboriginal groups, who have traditionally inhabited the Northern Regions of the country (Waldram, Herring & Young, 2006).

According to the 2006 census, there were 1,172,785 people in Canada who identified as an Aboriginal person (3.8% of total Canadian population) (Statistics Canada, 2008). The greatest number of Aboriginal people was in Ontario (242,495), British Columbia (196,075) and Alberta (188,365). Aboriginal people represented the greatest proportion of the total provincial population in Manitoba (15.5%), Saskatchewan (14.9%) and Alberta (5.8%) and the Territories, Yukon (25%), North West Territories (50.2%) and Nunavut (85%) (Statistics Canada, 2008). Between 2001 and 2006 the number of Aboriginal people in Canada increased 5.4% (Statistics Canada, 2008). The ten participants for this thesis are all from Alberta, Canada. Seven are treaty Indian and three are Métis.

Primarily, the history of contact between Aboriginal people in Canada and European explorers occurred through the fur trade and missionary activities (Waldram, Herring & Young, 2006). Aboriginal people became involved in the fur trade and initially involvement was to their benefit. Many found work near the fur trade settlements which often resulted in the establishment of permanent Indian residencies around the European settlements. This often resulted in intermarriage between European settlers and Indian women, unions resulting in “mixed-blood children”, and eventually a new population, the Métis (Waldram, Herring & Young, 2006). However, as time passed, and the major European organizations controlling the fur trade amalgamated into one, the Hudson Bay Company, the “position of the Indians engaged in the fur trade deteriorated dramatically” (Waldram, Herring & Young, 2006).

In 1867, The British North American Act was signed, creating Canada as a country. The signing also bound the new nation to the Royal Proclamation of 1763. The Proclamation established that Canada had to “obtain proper surrendering of Indian lands” (Waldram, Herring & Young, 2006). The treaty process was formed, and between 1871 and 1930 treaties were signed between Canada and Indian peoples. The treaties resulted in the government providing reserves of land for settlement. In relocating to reserves, Aboriginal people’s lifestyles became much more sedentary, contrasting their previous nomadic lifestyle (McLeod, 2007). The Inuit people in Northern Canada experienced extensive European contact like Aboriginal people in the south, but this occurred later. (Waldram, Herring & Young, 2006). In 1839, the Federal government declared the Inuit people to be included in the generic term ‘Indian’ for governing purposes, however, Inuit were not classified as ‘Indians’ under the Indian Act (Waldram, Herring & Young, 2006).

The process of colonization by European settlers and the subsequent government generally includes the signing of treaties, the loss-of-land, the relocation to reserves and the subsequent establishment of residential schools, among other results of European contact and control (Waldram, Herring & Young, 2006). Colonization has had devastating long-term effects on Aboriginal peoples. Contemporary disease rates and social risk behaviours have been linked extensively to the legacy of colonization (Farley, Lynne & Cotton, 2005; Kirmayer, Brass & Tait, 2000; Macdonald, Rigillo & Brassard, 2010; Moller, 2010; Waldram, Herring & Young, 2006).

3.1.1 Tuberculosis History in Canadian Aboriginals.

There is evidence that tuberculosis has existed for thousands of years (Stead & Dutt, 1983; Waldram, Herring & Young, 2006). Skeletal remains from 8000 BC and 2500 BC provide historical evidence of the disease (Waldram, Herring & Young, 2006). There is evidence that sporadic cases of tuberculosis existed in Aboriginal peoples before European contact but epidemic disease began to occur in Aboriginal communities only after contact in the 19th and 20th centuries. In the early 1870's the disease was relatively rare but by the 1880's tuberculosis was the primary cause of morbidity and mortality among Aboriginal individuals (Daschuk, Hackett & MacNeil, 2006). A recent study (Pepperell et al., 2011) identified a single *M. tuberculosis* strain in high frequency within Aboriginal populations in Ontario, Saskatchewan and Alberta. The same strain is dominant in TB cases in Quebec. Statistical analysis in the study was consistent with the conclusion that Quebec was a source population for this strain of tuberculosis into Aboriginal populations during the fur trade (Pepperell et al., 2011). Not only did the rates of tuberculosis increase through direct contact with the Europeans, but, the increase was also strongly influenced by the ecological, economic and political changes (Daschuk, Hackett & MacNeil, 2006). Relocation to reserves, residential schools, overcrowded housing, food insecurity and loss of traditional ways of life contributed to the high transmission of the disease and progression towards epidemic rates (Orr et al., 2007; Pepperell et al., 2011).

In the non-Aboriginal Canadian population, tuberculosis was a major cause of mortality and morbidity during the early 20th century. After that time, due to the discovery of effective treatments, improvement in living conditions, and public health measures, the rates of tuberculosis decreased (Orr et al., 2007). As described in chapter two (p.19), contemporary rates of TB show that Aboriginal people in Canada have a greater incidence rate of disease (27.8 per 100,000 persons compared to 1 per 100,000 persons in Canadian-born non-Aboriginal people) (PHAC, 2011).

3.2 New Zealand Indigenous People

This thesis includes interviews with both Maori and Pacific people from New Zealand. The following section provides a brief history of the Maori and Pacific people.

3.2.1 Maori People.

Maori are the Indigenous people of New Zealand and make up 15% of the total country's population (Oh, 2008). Historical research describes their ancestors as Polynesian (people of many islands) sailors, arriving in New Zealand between around 1150 AD (Belich, 1996). There has been much debate on the origins of the Polynesian culture, with historical arguments ranging from Asian, American Indian, Bolivian, British Columbian, Spanish, Portuguese and Basque influences. Modern research supports the view that the Polynesian peoples and language descended from areas between Taiwan and New Guinea (Belich, 1996).

The first significant European contact with New Zealand was by James Cook in 1769. Cook 'discovered' a land of independent tribes who identified themselves as *tangata maori* (the ordinary people) (Orange, 2004). Upon contact with the Europeans, the Maori tribes began trading with the sailors. This trade relationship expanded and continued as more Europeans came to New Zealand. Coexistence occurred between the Maori tribes and the Europeans for several years. The European impact was great in some areas and less so in others. In areas where the European impact was high, significant changes to the Maori traditional way of life occurred (Orange, 2004).

In the 1830's, Britain was interested in officially declaring New Zealand an English colony (Orange, 2004). The government wanted control to be transferred to Britain peacefully but questioned how the Maori tribes would react to the transfer of power and the loss of New Zealand as an independent state. It was decided that a treaty would be signed between the Maori leaders and Britain. By signing the Treaty of Waitangi, the Maori chiefs were meant to give up sovereignty to Britain, who would take total control of all transactions in land. In return, the Maori people were afforded protection, confirmed in their possessions, and promised "all the rights and privileges of British subjects" (Orange, 2004). Britain declared sovereignty over the entire country of New Zealand in May 1840 after the treaty was signed.

Maori and English accounts of the treaty differ and since the signing, the proper interpretation has continuously been debated. As time passed, and the British took more control over Maori life, Maori communities grew resentful and fearful for their future (Orange, 2004). Maori people were experiencing high rates of poverty, low-education, unemployment and health problems. Hostilities between the two groups increased, resulting in protests and civil wars in the mid and late 1800's. At the turn of the 20th century, the treaty continued to be a central factor in

the struggle to gain power from the government (Orange, 2004). In 1975, the Treaty of Waitangi Act was passed, and its reach was extended a decade later. This act had two primary goals: to educate people in New Zealand, both Maori and non-Maori, on the Treaty and to establish a formal process for settling grievances. The Act resulted in the formation of the Waitangi Tribunal, which has the power to investigate any Maori claims that the Crown has acted in breach of treaty principles (Orange, 2004). In 2002, the 1000th claim was filed and it is expected that the settlement of historical grievances will continue until 2020.

Historically, the Maori population experienced disproportionate rates of incarceration, poverty, unemployment, low education levels, and poor health compared to the Pakeha population. Maori and Pakeha differences in these rates continue in contemporary society. The relationship between poverty and health is strongly established (Hofrichter, 2003) and it is recognized that a key determinant of poverty for the Maori people is the lack of recognition of property and respect due to colonization (Oh, 2008). Colonization, and the subsequent loss of land that was used to sustain traditional lifestyles, resulted in the loss of an economic base and the abandonment of those traditional lifestyles (Rochford, 2004). It is said that Maori people “have been marginalized in our own homeland” (Rochford, 2004). Similar to the Canadian history of Aboriginal colonization, it is recognized that poverty, adverse living situations, and social inequity resulting strongly from colonization has contributed to the relatively high rates of tuberculosis in the Maori. It is also important to note that the many Maori communities of New Zealand have their own history and experience with colonization and thus the social determinants of health play out differently in different Maori communities (Rochford, 2004).

Though there is some debate, it is believed that tuberculosis did not exist in the Maori population until traders and whalers arrived in New Zealand in the early 19th Century (Finn, 2006). Throughout the late 19th Century, tuberculosis was prevalent in both the Maori and the Pakeha population. The Pakeha experienced a decrease in tuberculosis rates in the late 19th Century that the Maori did not experience. In 1942 in New Zealand, tuberculosis mortality in Maori was 422 per 100,000 compared to 39 per 100,000 in the non-Maori (Park, 2010).

3.2.2 Pacific People.

The Pacific population generally refers to the non- New Zealand and non-Maori people from a vast number of islands within the Pacific region who are living in New Zealand. They are not a homogenous group, as Pacific people come from many islands and from unique and

distinct communities (Ng Shiu, Park & Kearns, 2008). Pacific people in New Zealand consist of both migrants and New Zealand born residents. The majority of New Zealand Pacific people reside in Auckland, the largest New Zealand city in the North Island, and are from the south-west Pacific nations of Samoa, Tonga, Tuvalu, Cook Islands, Niue and Tokelau (Ng Shiu, 2006). Pacific people make up 6-7% of the total New Zealand population and 15% of the population of Auckland. (Ng Shiu, 2006).

At the end of World War II, mass migration to New Zealand occurred during the economic boom (Ng Shiu, Park & Kearns 2008). Initially, the new Pacific migrants were integrated into the unskilled and semi-skilled working class. More recently, some have become part of the middle class (Ng Shiu, Park & Kearns, 2008). However, despite the success by some, Pacific people are disproportionately represented in the lowest socioeconomic class (Ng Shiu, 2006). In 2003, the rate of Pacific unemployment was 7.9% compared to the national average of 4.6% (Ng Shiu, 2006). Pacific people also experience high rates of housing overcrowding and over-representation in state housing and rental accommodations. Similar to the poor social conditions of both the Maori and Canadian Aboriginal people, poverty and its related experiences in the Pacific populations contribute to the high rate of illness and disease, including tuberculosis (Ng Shiu, 2006).

Tuberculosis spread to the Pacific Islands from Europe during the European empire expansion and colonization (Bates & Stead, 1993). In the Pacific Islands, tuberculosis was a major problem in many areas until the mid and late 19th Century. In the Pacific Islands themselves, the rates of tuberculosis differ significantly amongst the different nations (Park, 2010; Resture, 2010).

3.3 Indigenous Frameworks of Health

As the previous chapter described, it is crucial to consider social determinants of health when examining tuberculosis and different disease factors. This thesis employs a social determinants of health perspective when examining tuberculosis transmission, but in addition, it is also necessary to apply frameworks that consider the unique social determinants of Indigenous health related to the impacts of the colonization experience and that are embedded in Indigenous perspectives on health. These frameworks of health are similar to the previously described non-population specific framework of health (figure 2.3, p.17) but involve a more in-depth holistic

view of health. A holistic concept of health that reflects physical, spiritual, emotional and mental dimensions is often embraced by Indigenous ideologies (Reading & Wien, 2009) and thus it is important that the framework utilized when exploring aspects of health of Indigenous people is congruent with these ideologies and perspectives. Although the non-Indigenous framework (figure 2.3, p.17) includes a category for cultural and societal norms and values, the following Indigenous-specific frameworks more specifically describe these norms including a holistic view of health described above. Because this thesis explores the TB transmission experience of Indigenous people in both Canada and New Zealand, it is also informed by Indigenous health frameworks specific to each.

3.3.1 Canadian Aboriginal Framework of Health.

In Canada, the study is guided by two frameworks: the Assembly of First Nations (AFN) Wholistic Policy and Planning Model and the National Aboriginal Health Organization's (NAHO) list of the social determinants of Aboriginal health.

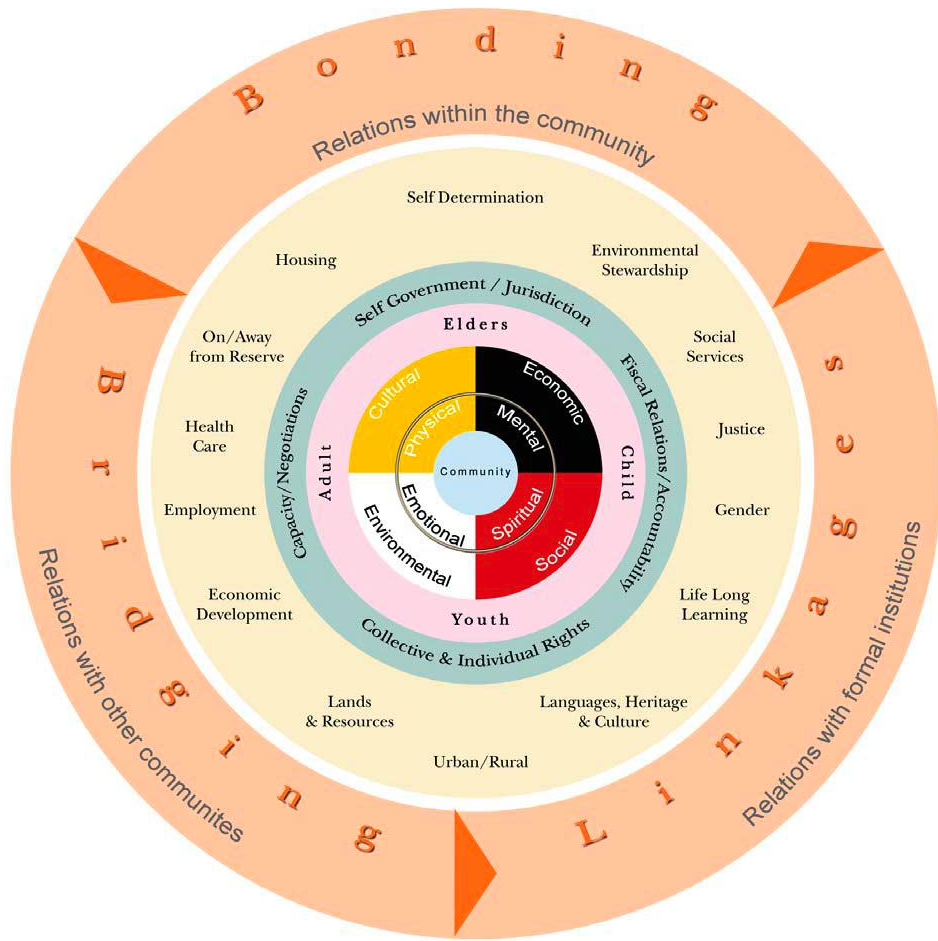
The AFN model (figure 3.1, p.30) outlines the components that are essential to Aboriginal community health and includes a representation of the determinants of health. The determinants of health outlined in the model include health care, on/away from reserve, housing, self-determination, environmental stewardships, social services, justice, gender, life-long learning, languages, heritage and culture, urban/rural location, lands and resources, economic development and employment (AFN, 2005). The NAHO determinants of health include some of the same determinants as the AFN model but incorporate further historical and cultural considerations such as colonization, globalization, migration, cultural continuity, access, territory, poverty and self-determination (NAHO, 2007). By utilizing a framework that was developed *by* Aboriginal people *for* Aboriginal people the analysis focuses attention on social determinants that are unique to *Aboriginal* health in Canada and that are also linked to the colonization experience that would not be considered if a broader social determinants of health framework was used.

3.3.2 New Zealand Indigenous Frameworks of Health.

Analysis and interpretation of the Indigenous New Zealand interviews was guided by Maori and Pacific people's health perspectives.

3.3.2.1 Maori people.

The Maori model of health – *Whare Tapa Wha*, was developed in response to the disparities in both health and social indicators between Maori and Pakeha and the recognition that a holistic framework that addresses biomedical, social, political and environmental influences on health was necessary for evaluating Maori health. The *Whare Tapa Wha* model (Table 3.1, p.31) was developed by Dr. Mason Durie, who drew together different concepts of Maori health (Durie, 1994). The model compares health to the four walls of a house; each ‘wall’ is necessary for strength and symmetry (Durie, 1994). The four realms of the *Whare Tapa Wha* model are the *taha tinana* (physical), *taha hinengaro* (*hinenkaro* in the South Island) (emotional), *taha whanau* (social) and *taha wairua* (spiritual). The model “reflects the unified view of the universe, which is fundamental to the Maori worldview”. As a result, this holistic view of health allows Maori people to take more ownership over their health (Rochford, 2004) and Durie notes that this model is a “view of health which accords with contemporary Maori thinking” (Durie, 1994).







- L e g e n d**
-  Medicine Wheel
 -  Lifespan
 -  First Nations Self-Government
 -  Health Determinants
 -  Social Capital

Figure 3.1: First Nations Wholistic Policy and Planning Model. This framework represents the determinants of health to First Nations and is used in the Canadian analysis of qualitative interviews to provide context and guide the analysis on factors associated with the experience of TB and TB transmission (Assembly of First Nations, 2005).

Table 3.1: The *Whare Tapa Wha* model (Durie, 1994).

	<i>Taha Wairua</i>	<i>Taha Hinengaro</i>	<i>Taha Tinana</i>	<i>Taha Whanau</i>
Focus	Spiritual	Mental	Physical	Extended family
Key Aspects	The capacity for faith and wider communion	The capacity to communicate, to think and to feel	The capacity for physical growth and development	The capacity to belong, to care and to share
Themes	Health is related to unseen and unspoken energies	Mind and body are inseparable	Good physical health is necessary for optimal development	Individuals are part of wider social systems

Similar to the Assembly of First Nations framework of Aboriginal holistic health that provides a background context and guides the analysis of the Canadian qualitative interviews, this Maori framework is important to consider in engaging with the Maori interviews I accessed in this project. It is well-accepted that culture and socioeconomic conditions are important factors in health and this framework highlights the factors that Maori themselves have identified as contributing to their health. These factors need to be considered when attempting to gain an understanding of health and disease, including the experience of tuberculosis and the conditions of disease transmission. The two frameworks are similar in that they consider colonization and its residual effects, including spiritual factors and other social effects on broader health. The goal of both the frameworks is to allow the Indigenous communities to take ownership of their health and facilitate an understanding of health that is consistent with their world views: one that is not solely based on a biomedical and physical view of health that dominates the Western thought and subsequently mainstream government health services in both Canada and New Zealand. The Maori health model was introduced at a time when Maori had an interest in redefining health in their own terms and have a more active role in shaping health services (Durie, 1994).

3.3.2.2 Pacific People.

Given the number of countries and subsequently the diverse cultural groups that are included in the category of Pacific people in this thesis, there is no one Pacific health model that truly describes the experience or view of health within all of these groups. I had access to five interviews with Pacific individuals with, or who spoke of a family member with, pulmonary TB.

Two of these individuals were Tuvaluan, one was a Cook Islander and two were Samoan and thus there is not one Pacific framework of health that may describe all of these Pacific participants' views on health. However, it has been noted that there are two fundamental similarities within different Pacific views of health: a holistic view of health, and the notion that health is a family affair rather than an individual concern or situation (Ng Shiu, 2006).

Similar to the Canadian Aboriginal and New Zealand Maori conception of holistic health, Pacific cultures consider health to be determined not only by one's physical well-being, but also through their social, spiritual and environmental well-being. Health therefore can be determined not only by natural causes but also due to supernatural sources and factors related to social relationships (Ng Shiu, 2006). Secondly, health is considered to be a family affair and thus health-seeking behaviours are influenced by the opinions of the whole family (Ng Shiu, 2006). Additionally, health beliefs consistent between several Polynesian communities include perspectives of health that differ from conceptualizations of biomedicine, the role of traditional living in understanding health and the place of spirituality and religion in health and illness causation (Capstick et al., 2009).

3.4 Indigenous Social Determinants of Tuberculosis

The previous chapter discussed general social determinants of tuberculosis and this section builds on those descriptions with a more in-depth examination of what research has shown about how social determinants of health play out for Indigenous peoples.

3.4.1 Canadian Aboriginal Housing.

The *Canadian Charter of Rights and Freedoms* does not make explicit any laws regarding housing, and the Canadian government has never recognized a universal entitlement for government support of housing as a treaty or Aboriginal right (Indian and Northern Affairs Canada [INAC], 1996). Housing rights and responsibilities are often left up to interpretation by governments at all levels (Porter, 2003). First Nation status Indians reside in either reserve communities, non-reserve communities or they move between both.

Those individuals who do stay on reserves often experience sub-standard living conditions. Aboriginal reserves are often small and resource poor and some offer little more than housing sites. Often the houses are built to lower standards than off-reserve homes in Canada (Barsh, 1994). These houses deteriorate more quickly over time due to poor construction,

improper maintenance and overcrowding, yet there is often limited funding and resources for repairs (Statistics Canada, 2008). Reports from the 2001 Canadian Census Housing Series found that 10.3% of on-reserve homes were over-crowded (defined as an insufficient number of bedrooms for the number of household occupants). On reserves, 50% of Aboriginal houses fell below the Canadian Mortgage and Housing Corporation (CMHC) housing standards for suitability and adequacy, 15% were over-crowded and 23% were in need of major repairs (CMHC, 2001). Sub-standard living conditions may facilitate increased disease transmission as well as result in social stress and mental conditions that decrease the ability of an individual's immune system to defend against infection. Research studies have noted the association between housing density, overcrowding and rates of tuberculosis (Clark, Riben & Nowgesic, 2002; Larcombe et al., 2011).

In urban areas, individuals may also face poor housing conditions and/or homelessness. The measures of housing hardship, including affordability and crowding, are considerably worse for Aboriginal than non-Aboriginal people in urban settings (Walker, 2008). In addition, discrimination towards Aboriginal people by landlords and housing companies can be a barrier to obtaining safe and affordable housing (Walker, 2008). Understanding the living conditions of individuals with tuberculosis is important in understanding transmission patterns and the burden of tuberculosis within each community.

3.4.2 New Zealand Indigenous Peoples Housing.

In 2006, approximately 13% of Maori households were overcrowded (Flynn, Carne & Soa-Lafoa'i, 2010). Although a decreasing trend is seen in Maori housing overcrowding in the last twenty years, the disparity between levels of crowding in Maori households compared to European⁵ households continues. Almost six times as many Maori people live in crowded households as compared to European people. The decline in Maori housing overcrowding has occurred at a greater rate than the decline in overcrowding in Pacific households in New Zealand (Flynn, Carne & Soa-Lafoa'i, 2010). 2006 data reports that approximately 12% of the Maori population resided in subsidized New Zealand Corporation housing compared to 2% of the New Zealand European population and 26% of the New Zealand Pacific population. Over time, housing has become less affordable for Maori and Pacific people. In 2004, housing affordability

⁵ The 2005 Ethnicity Standard introduced by Statistics New Zealand outlines how government agencies report on ethnicity data. 'European' is one option within the standard ethnicity categories (Flynn, Carne & Soa-Lafoa'i, 2010).

was similar for New Zealand Europeans, Maori and New Zealand Pacific people, but since that time the affordability of housing for the Maori and Pacific people has decreased at a greater rate than for the New Zealand European people (Flynn, Carne & Soa-Lafoa'i, 2010). In 2006, 43.3% of Maori people lived in owner-occupied homes compared to 69.7% of the New Zealand European population.

Similar to Canadian Aboriginal people, Maori and Pacific people in New Zealand tend to be concentrated in “pockets of poverty and deteriorated housing”. Additionally, Pacific people and Maori are more likely to live in rental properties and, as has been described for urban Canadian Aboriginal people, Pacific people and Maori people experience discrimination from landlords and housing organizations (Kearns, Smith & Abbott, 1991).

3.5 Social Determinants of Health and Barriers to Receiving Medical Care

As tuberculosis infection is transmitted through bacteria propelled into the air through coughing and other mechanisms of force, medical treatment that reduces cough and kills or inhibits the bacterium is crucial to reducing the transmission potential. Time-of-diagnosis and initiation of effective treatment are important factors in understanding transmission patterns and potential.

3.5.1 Canadian Research on Barriers to Receiving Medical Care.

Within the Canadian Aboriginal population, several barriers to accessing health care have been identified (Benoit, Carroll & Chaudhry, 2003; Gao et al., 2008; McKee et al., 2009). It is necessary to understand the barriers that may act to prevent an individual from accessing health care and thus increase the time that individual is able to transmit the disease to other people within their community and social networks. Research in British Columbia, Canada noted several barriers to accessing health care for Aboriginal people in regards to diabetes care (McKee et al., 2009). The study reported that geographical barriers, cultural barriers, educational barriers and financial barriers are factors that may influence a patient's ability to seek medical care and receive effective treatment (McKee et al., 2009). Similar to the critical nature of treatment for diabetes, effective medical care is necessary in treating tuberculosis and thus understanding and overcoming these barriers is crucial in efforts focused at decreasing the burden of the disease. Barriers such as geographical isolation and community remoteness may limit an individual's ability to access health services for tuberculosis diagnosis (Stirling & Enarson, 2007). Depending

on the facilities offered within an individual's own community or their ability to travel to larger centers for more specialized medical services, individuals may or may not be able to obtain medical care upon symptom development. In addition, remote communities often have limited health resources, with focus largely on primary care, and thus a lack-of-tuberculosis-education may decrease an individual's ability to recognize disease symptoms and understand the importance of early diagnosis. A 2002 study found that 16.9% of First Nation adults living on reserve felt that the health care provided on the reserve was inadequate (Reading & Wien, 2009). Additionally, 13.5% felt that the health services were not culturally appropriate while 13.7% could not afford the transportation costs required to get to the health services and 7.1% could not afford child care costs associated with having to go to a health care facility (Reading & Wien, 2009).

Colonization, and the legacy of residential schools and tuberculosis sanatoriums, may result in negative attitudes towards Western medicine and mainstream government health services and discourage an individual from seeking help from these health services if they develop disease symptoms. Research has noted that students experienced feelings of inferiority and helplessness while at residential schools and these feelings can carry over to their interactions with their contemporary health providers (Towle, Godolphin & Alexander, 2006). Other Aboriginal residential school survivors believed that health providers were involved with the federal government in plots to kill Aboriginal people. These suspicions and mistrust may continue to present day interactions with medical professionals (Towle, Godolphin & Alexander, 2006). These attitudes may also be passed on to future generations, increasing the number of individuals with negative attitudes towards health services and increasing the number of individuals who will not seek health attention upon becoming sick.

In addition, a residual effect of residential schools and sanatoriums is a loss-of-understanding of healthy family functioning and responsibilities. Children were separated from their parents for many years and thus not exposed to positive family roles, relationships and functions (Reading & Elias, 1999). This may result in individuals making poor life decisions leading to poor health or health-seeking behaviours or individuals not having the skills for healthy parenting. Additionally, children of residential schools were ill-prepared for educational experiences beyond residential school and life and work opportunities in Canadian society

(Milloy, 1999). A chief of the Albany First Nation described the enduring effects of residential schools in this way:

Social maladjustment, abuse of self and others and family breakdowns are some of the symptoms prevalent among First Nation Babyboomers. “Graduates” of the “Ste. Anne’s Residential School” era are not trying and often failing to come to grips with life as adults after being raised as children in an atmosphere of fear, loneliness and loathing.

Fear of caretakers. Loneliness, knowing that elders and family were far away. Loathing from learning to hate oneself, because of repeated physical, verbal or sexual abuse suffered at the hands of various adult caretakers. This is only a small part of a story. (Milloy, 1999).

Contemporary studies have noted beliefs and perceptions of tuberculosis are based on historical processes associated with tuberculosis and tuberculosis treatment including sanatoriums, isolation and separation (Gibson et al., 2005; Macdonald, Rigillo & Brassard, 2010). A 2005 study noted that Aboriginal people from communities in Alberta felt that healthcare professionals treated them differently due to their TB as well as an overall stigma against Aboriginal people as a group by non-Aboriginal people (Gibson et al., 2005). For many, tuberculosis is associated with colonization: “it’s like a White person’s disease that was brought in . . . to take out the First Nation’s people” (Macdonald, Rigillo & Brassard, 2010). If these perceptions and associations persist in Aboriginal communities, individuals may be reluctant to seek out health care, as it will highlight their disease within their community or they may not trust the government-run health systems within their community. Additionally, studies have noted the silence that exists around TB within some communities due to historical experiences and the desire not to revisit those negative experiences (Macdonald, Rigillo & Brassard, 2010). The collection of these TB related associations and behavior may have a negative impact on individuals beliefs regarding tuberculosis and treatment and may contribute to an individual not being aware of TB symptoms or not seeking health treatment, increasing the time that they are without proper treatment and still infectious (Gibson et al., 2005).

Another long-term effect of colonialism is the destruction of Aboriginal peoples' relationship with the environment and with their land. Aboriginal people were forbidden to engage in traditional activities such as hunting, trapping and fishing and Indigenous authors have suggested that the traumas subsequently experienced by Aboriginal people are rooted in the dislocation from their land (Reading & Wien, 2009). Relationship with environment, through harvesting, hunting, fishing, etc, has been linked with an increase sense of self-reliance and greater overall health (Reading & Wien, 2009).

Currently, only 0.3% of Canadian doctors are Aboriginal and therefore the majority of health care will continue to be delivered by non-Aboriginal health professionals (Towle, Godolphin & Alexander, 2006). Racism and a lack-of-cultural competence by health professionals may deter an individual from seeking medical attention. Understanding doctor-patient communication is vital in recognizing potential barriers to seeking health care (Towle, Godolphin & Alexander, 2006). Aboriginal individuals have noted that it can be difficult to trust their physicians if there is no understanding or recognition of their history and what they have experienced. Patients have noted that if the doctor took time to learn their history and their culture then trust could be established (Towle, Godolphin & Alexander, 2006). In addition, other social situations such as unemployment, education, food insecurity and substance abuse and addiction are considered in this thesis as potentially contributing to increased transmission (Reading & Wien, 2009).

3.5.2 Social Determinants of Health for Indigenous People in New Zealand.

Like the Canadian research on tuberculosis, much investigation of tuberculosis in New Zealand has acknowledged the role of social factors in both the development of the disease and the experience of treatment. Previous research theses have focused on the experience of tuberculosis amongst different ethnic groups, the experience of tuberculosis treatment in different groups, the perceptions of healthcare workers towards tuberculosis patients and the experience of tuberculosis through different political, geographical and historical lenses (Finn, 2006; Hay, 2010; Oh, 2005; Resture, 2010). Although these projects did not focus specifically on tuberculosis transmission, this thesis reconsiders these interviews from the perspective of transmission, revealing factors that may be associated with tuberculosis transmission, independently identified as being relevant within the New Zealand Indigenous experience of tuberculosis.

Social conditions such as tuberculosis stigma, family relationships, tradition and cultural practices, socioeconomic status, housing, patient/health care relationships and cultural competence, alcohol and drugs, criminal activity and access to health services are all issues that have been identified in relation to tuberculosis in New Zealand (Hay, 2010; Littleton & Park, 2009; Miller, 2007; Ng Shiu, 2007; Oh, 2005). These factors may result in delayed diagnosis, due to either patient and/or health care delay, or decreased treatment compliance. This in turn will increase the time a person is infectious, thereby potentially increasing the number of contacts that may become infected. A public health physician in the Auckland area, who both works with tuberculosis patients and conducted her Master's research on the experience of having tuberculosis treatment in Auckland, believes that delayed diagnosis is the number one reason as to why tuberculosis transmission occurs (Hay, personal communication, September 7, 2010). Additionally, similar to the Canadian situation, these factors acting as barriers to accessing health care and educational services may be rooted in both historical and contemporary experiences and may contribute to the transmission of tuberculosis in the New Zealand Indigenous population.

An investigation of recent TB outbreaks in New Zealand communities confirmed and highlighted the importance of social determinants of health in relation to TB transmission. In one case of a TB outbreak in a Pacific church group in Auckland, a major issue surrounding delay between identifying the index case and the source case was denial and stigma surrounding the disease within the community. In addition, members of the community feared repercussions from identifying their contacts and this also led to a delay in screening and identifying the source case (Hill & Calder, 2000).

In another outbreak within a Pacific community in Auckland, the importance of early diagnosis and initiation of treatment in adult TB cases as a means of preventing TB transmission was highlighted (Voss et al., 2006). The study highlights the importance of early diagnosis and initiation of treatment in adult TB cases in order to prevent TB transmission. Issues that arose during the investigation included incomplete divulgence of contacts and refusal of contact assessment. The contact investigation was hampered by inter-household movement and difficulties in tracing people. Additionally, surnames are not of great importance to Tuvaluans who may use different names in different contexts, potentially causing further difficulty in contact-tracing (Sagaa Malua, personal communication, November 1, 2010). Further community

issues stemming from the Pacific Island country may have exacerbated the situation. Tuvalu is small and resource poor and many members have tried to immigrate to new countries, including New Zealand. Often, families do not gain permanent residency and over-stay their allotted time in the country. In this community, information obtained by the authors confirmed that some of the involved families may have unclear residency status, which may have contributed to their unwillingness to work with public health officials in fear of their residency status and repercussions (Littleton & Park, 2010). In addition, many of the members were believed to have limited financial resources and make little use of government health or education services. Again, for some this may be due to uncertainty surrounding their residency status. Additionally, Tuvaluans moving to New Zealand often find jobs as poorly paid workers and thus unemployment and underemployment is a problem. As a result, some Tuvaluans live in crowded conditions, participate in informal economies and eat a restricted diet (Littleton & Park, 2010).

Finally, other similar outbreak reports highlight the issues surrounding socioeconomic deprivation, crowded living conditions, limited utilization of health-care, treatment non-adherence and delayed diagnosis in relation to TB transmission in Auckland (De Zoysa & Shoemack, 2001; McElnay, Thornley & Armstrong, 2004; Sexton, Perera & Pandey, 2008).

3.6 Summary

This chapter provides detail on the history of Indigenous people in Canada and New Zealand, and what is known about their experience with TB. It introduces the Indigenous frameworks of health utilized in this thesis and examines the research around specific social determinants of health for Indigenous people. The following chapter outlines the data collection and analysis that occurred in both Canada and New Zealand.

Chapter Four: Methodology

This section outlines the data collection and data analysis that occurred for this thesis. This thesis is unique in that it utilizes qualitative secondary data, ultimately analyzing twenty-one interviews with TB patients (and family members) in Canada and New Zealand. Accordingly, the following description of the data collection process primarily outlines the techniques used by other researchers of the *Determinants of Tuberculosis Transmission* research team in Canada. In New Zealand interview data were drawn from completed theses and supplemented with discussions that occurred with the authors of the theses and others involved in TB research. This chapter also includes a discussion on the methodological approach for this project, phenomenology, and discusses limitations of phenomenology and the utilization of phenomenology with secondary data.

4.1 Data Collection in Canada

The *Determinants of Tuberculosis Transmission* (DTT) research project is made up of expert researchers in the areas of molecular techniques, tuberculosis control, HIV-TB interactions, epidemiology methods and Aboriginal health research and community members from across Alberta, Saskatchewan and Manitoba. The project involved Aboriginal faculty and staff from the beginning and developed Provincial Network Committees (PNCs) consisting of Aboriginal experts including Elders, Indigenous healers and health-care providers (Boffa et al., 2011). The PNCs were created and expanded from an initial Aboriginal consultative committee that existed within the TB Program Evaluation and Research unit in the Department of Medicine at the University of Alberta. Similar committees were created in both Manitoba and Saskatchewan consisting of health care workers, Elders, traditional healers, patients and representatives from Aboriginal and governmental stakeholder groups. The PNCs were developed to represent Aboriginal populations throughout the study in decision making processes, developing research questions, creating interview tools and interpreting findings (Boffa et al., 2011). The PNCs were developed “to avoid research that constructs ‘an image of sick, disorganized communities [that] can be used to justify paternalism and dependency’ and instead to develop research that supports the ‘new epidemiological research model’ that espouses ‘high quality’ information through Aboriginal participation in all aspects of the research” (Boffa et al., 2011).

The goal of the cross-provincial collaboration is to unravel the complexities of tuberculosis transmission through molecular epidemiology, qualitative inquiry and traditional epidemiological methods. This project is one of many projects within the DTT project researching tuberculosis transmission from different perspectives. The DTT project received ethical approval from all major Aboriginal organizations on the prairies, from the Universities of Alberta, Calgary, Saskatchewan and Manitoba and from Health Canada. As my thesis is an analysis of secondary data in which the DTT project had already obtained ethics approval for, I received an ethics exemption from the University of Saskatchewan Behavioural Research Ethics Board.

The data collection occurred by trained members of the DTT project, researchers, study coordinators and assistants, in the three provinces of the study: Alberta, Saskatchewan and Manitoba (figure 4.1.p.41). The data collectors conducted quantitative surveys and qualitative interviews with the individuals who agreed to participate in the study.

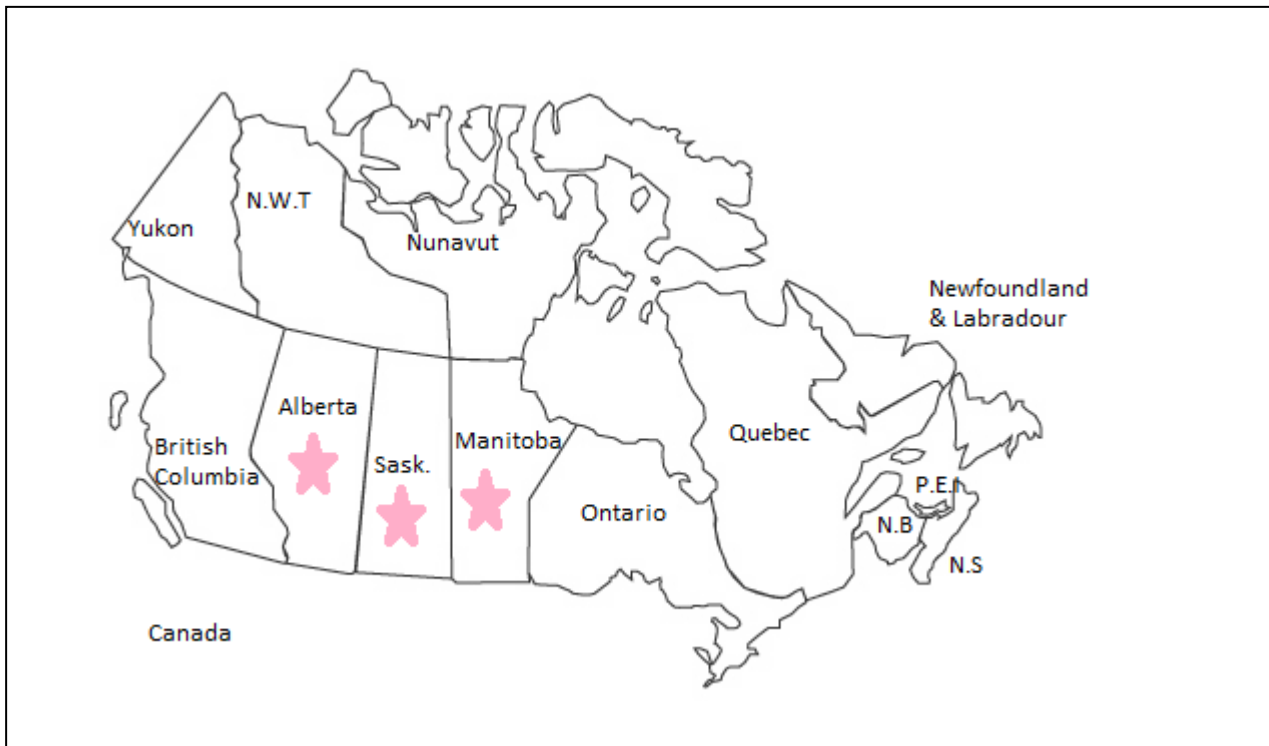


Figure 4.1: Map of Canada. Data was collected for the Determinants of Tuberculosis Transmission project in Alberta, Saskatchewan (Sask. on map) and Manitoba.

4.1.1 Study Population.

The study population included all individuals on the Canadian Prairies diagnosed with tuberculosis between July 1, 2006 and December 31, 2010. Transmitter and non-transmitter groups were identified from a subgroup of Canadian-born adults (>14 years) diagnosed with culture-positive pulmonary tuberculosis between January 1, 2007 and December 31, 2008. Further, they were identified from members of the subgroup who were sputum smear-positive, were Aboriginal, and had participated in the qualitative interviews. Culture positive respiratory cases that are smear-positive are approximately four times more likely to transmit than smear-negative cases (Behr et al., 1999). All TB patients consenting to participate in the study were followed up both prospectively (two years) and retrospectively (three months) from the time of their diagnosis in order to observe each source case's contacts and their diagnosis status. Patients meeting the criteria for the study were identified through tuberculosis control physicians in the three provinces. If the patients met the inclusion criteria they were approached by the tuberculosis control physician to determine their willingness to be seen by the study coordinator. If the individual agreed, they met with the study coordinator who explained the project in detail and invited them to participate. If they agreed to participate in the study, an informed consent form was signed by the individual. A centrally located study coordinator in each province administered both the quantitative survey and qualitative interview with the consenting participants. Every patient was given the opportunity to ask questions and voice their concerns. For this master's study I accessed interviews and survey data of ten Alberta TB patients who underwent quantitative surveys and qualitative interviews. All ten patients had classical and cavitary chest x-rays representing the most typical radiographic presentation.

4.1.2 Data Sources.

DNA fingerprinting of all tuberculosis isolates was performed at the National Reference Centre for Mycobacteriology, National Microbiology Laboratory. The socio-economic status of survey cases were approximated using census and INAC data from 2006 and cases were mapped to reserve or off-reserve communities. The major data collection tools were the quantitative survey and the qualitative interview.

4.1.2.1 Quantitative Surveys.

The quantitative questionnaires were conducted with all adult culture-positive pulmonary TB patients who were diagnosed beginning February 1, 2007. They were conducted in two parts

to systematically collect data on the tuberculosis case individuals. The first part of the questionnaire was collected in face-to-face meetings with study participants while the second element used data collected from the respective provincial tuberculosis registries. The questions of the quantitative questionnaire were grouped into four categories focused on how tuberculosis transmission occurs: (i) diagnosis delay, (ii) environmental circumstances, (iii) number and susceptibility of contacts and (iv) program malfunction. A more detailed list of the questionnaires on the survey can be found in appendix I. Participants were asked to provide information on such factors as their symptoms, duration of symptoms before diagnosis, alcohol and drug use, work and travel history and their perception of their community health services. The quantitative surveys were also used as a means of introducing and building a rapport between the study coordinator and the participant and allowed for an opportunity for the participant, if they were also smear-positive, to be invited to participate in the qualitative component of the study. The participants who filled out the questionnaire were given an honorarium of twenty-five dollars in recognition of their participation. The information from the quantitative surveys was compiled into a database hosted by the University of Alberta that identifies participants only by a unique identifier, ex. AB0024.

4.1.2.2 Qualitative interviews.

Any smear-positive participant who answered the questionnaire was asked to participate in the qualitative component of the project. In total, fifty-five interviews were conducted across Alberta, Saskatchewan and Manitoba. The three provincial study coordinators, all trained in qualitative methodology, conducted semi-structured interviews with the participants shortly after their diagnosis. These interviews occurred in either a hospital environment or the participant's home, depending on where the participant was receiving treatment. All the Alberta interviews took place in an Alberta hospital. The qualitative interviews asked the participants to describe their daily life before having TB, their experience with TB, their views of health and sickness and their opinions about TB transmission and what could be done to stop it. A more detailed list of the interview questions and rationale for the qualitative interview tool can be found in appendix II. The interview tool was developed by the provincial study coordinators, the academic investigators of the DTT project and the PNCs.

4.1.3 Working with the Secondary Data.

Since a major goal of this thesis is to better understand the social factors that influence tuberculosis transmission, prior to commencing analysis, patients were categorized as transmitters or non-transmitters. This was done using both molecular and epidemiological data to create a ranking system to order participants into a hierarchy from greatest transmission to least transmission events.

In June 2010 I travelled to the TB research group at the University of Alberta and worked with the members to access and organize the molecular and contact tracing data and create the two groups (individuals with many transmission events and individuals with few or no transmission events). The individuals included in this study to be divided into two groups for comparison had to have smear-positive pulmonary tuberculosis (an inclusion criteria of the larger DTT study to participate in the qualitative component of the study), have been diagnosed between January, 2007 and December, 2008 and have a classical and cavitary chest x-ray, representing the most typical radiographic presentation for pulmonary tuberculosis. I used a ranking system in which four categories of transmission events were considered and ranked. A source case was assigned four points if it could be proven, using molecular and epidemiological data, that one of their contacts was a secondary case. I examined each source case and used the DNA fingerprint of the *Mycobacterium tuberculosis* isolate to compare between the source case and their contacts. If the source case and a contact had an identical isolate, the contact had been diagnosed after the source case and the two could be linked through familial, social or geographical relationships, it was considered a secondary case. Three points were assigned to the source cases if a close contact was considered to be a second case, but this could not be confirmed through molecular means. A source case was assigned two points if they had a contact that had a tuberculin skin test (TST) conversion and was thus considered a tuberculin converter. A TST conversion occurs if an individual's previous TST was negative (< 5mm induration) while their most recent skin test is positive (greater than or equal to 10 mm induration) (Menzies & Khan, 2007). Circumstances of the case and their environment are considered when evaluating TST conversions. Finally, a source case was assigned one point if a close contact was a new positive but did not have a previous TST to compare with.

It is important to note that a participant of this project is considered to be a transmitter or non-transmitter based only on the aforementioned methods and solely for this project as it was

necessary to create two contrasting groups for comparison. The terms are not meant as labels and throughout the thesis every effort is taken to ensure that specific participants or groups of participants are not identified through any form of negative labelling.

Table 4.1 (p.45) describes the ten Alberta patients in this thesis and their points based on the above criteria. After the points had been assigned a clear cut-off point emerged.

Table 4.1: Alberta TB patients used in this study showing their point rank and their assignment into transmitter and non-transmitter groups.

Pseudonym	Interview ID	Sex	X-ray	Total Close Contacts	Secondary cases ⁶ (4 points)	Secondary cases ⁷ (3 points)	Tuberculin Converters (2 points)	Recent Positive TST (1 point)	Total points
TRANSMITTERS									
Catherine	AB0024	Female	classical, cavitory	74	2	1	8	7	34
Robert	AB0040	Male	classical, cavitory	15	2	3	0	3	20
Joseph	AB0011	Male	classical, cavitory	37	0	0	4	7	15
David	AB0022	Male	classical, cavitory	77	1	1	2	4	15
Adam	AB0006	Male	classical, cavitory	8	1	0	1	1	7
NON-TRANSMITTERS									
Rebecca	AB0038	Female	classical, cavitory	16	0	0	1	1	3
Nathaniel	AB0032	Male	classical, cavitory	15	0	0	0	1	1
Rosemary	AB0004	Female	classical, cavitory	6	0	0	0	0	0
Aiden	AB0016	Male	classical, cavitory	22	0	0	0	0	0
Mark	AB0021	Male	classical, cavitory	2	0	0	0	0	0

Table 4.1 (p.45) shows the division of the Alberta participants into transmitter and non-transmitter groups. A pseudonym was given to each individual while the interview ID corresponds to the identification given to the participant by the interviewer. The transmitter group had point scores ranging from seven to thirty-four. For example, Catherine, a female

⁶ Molecular confirmation.

⁷ No molecular confirmation.

patient with classical and cavitary, smear-positive pulmonary tuberculosis, had a total of thirty-four points. She had two close contacts who were confirmed to be secondary cases based on both molecular matching of the *M. tuberculosis* DNA isolate between her and the contacts, and by taking into account conventional epidemiological relationships that could link the two individuals to her. The two close contacts that were secondary cases with molecular confirmation contributed eight points to Catherine's transmission rank. She also had one secondary case that could not be confirmed by molecular confirmation, but could be linked through epidemiological relationship tracing, contributing an additional three points. Catherine had eight tuberculin converters within her close contact list for a total of sixteen points and seven close contacts that were recent positives for a total of seven points. In total Catherine was assigned thirty-four points that reflect her transmission events. Contacts of the source cases were identified through public health contact tracing. Details surrounding the contacts of each source case beyond their TB development information was not available to me.

Table 4.1 (p.45) also notes that the non-transmitter group had individuals with point scores ranging from three to zero points. For example, Rebecca, a female patient with classical and cavitary, smear-positive pulmonary tuberculosis, had a total of three points. She had one tuberculin converter and one recent positive within her close contacts for a total of three points. Three individuals within the non-transmitter group, Rosemary, Aiden and Mark were determined to have no transmission events based on evaluation of their contacts and were therefore assigned zero points. There were no individuals within the non-transmitter group that had contacts diagnosed with TB disease and thus no non-transmitters had any secondary cases within their contacts.

Based on the previously described data sections, including the data collection that gathered information on the ten TB patients and the ranking system to separate individuals with pulmonary tuberculosis into those with many transmission events, the transmitter group, from those with few or no transmission events, the non-transmitters, I had two groups for comparison within the Canadian component of the project for a total of ten qualitative interview and surveys to analyze. Comparing two groups would allow me to address my research objective of understanding the differences in the experience of the social determinants of health for transmitters and non-transmitters.

4.2 Data Collection in New Zealand

In New Zealand, I worked with a research team with extensive experience in tuberculosis history and anthropology. As the greater New Zealand project differed from the greater Canadian project in both research goals and methods as well as in available resources, a comparative project between tuberculosis transmitters and non-transmitters within the Maori and Pacific people was not possible. However, extensive data was still available for analysis from a transmission perspective and comparison with the two groups in Canada. Demographic data on New Zealand tuberculosis cases, qualitative interviews from previous research projects, and published reports on tuberculosis outbreaks and molecular characteristics of clusters were available for examination. The objective of the New Zealand component of the project was modified accordingly based available data and relevance to the Canadian component. The objective was to examine the experience of TB within Indigenous people in New Zealand and compare the social determinants of health linked to transmission and non-transmission in Canada.

The subsequent New Zealand analysis is based on three sources of data: (1) qualitative interviews from former students within the University of Auckland TB project, (2) discussions with those students and information from their theses and (3) a discussion with a TB physician in Auckland and access to her thesis. I had access to six interviews conducted with Maori pulmonary TB patients (and family members) and five interviews with Pacific TB patients (and family members). Additionally, I was able to speak informally with the two former students who had conducted the interviews. They were able to provide me additional information regarding the interview participants, barriers and limitations they faced in their data collection and analysis and additional information regarding their participants and the interview experience. From the discussion with the physician and information from her thesis, I accessed a number of factors that the physician identified within her analysis that may be relevant to transmission.

4.2.1 Qualitative Interviews.

I accessed the transcripts of six qualitative interviews that were conducted by Moana Oh, a former master's student who completed her thesis in 2005. Five of the interviews were with Maori participants diagnosed with pulmonary tuberculosis within the Auckland public health region from 2002 to 2005 and one interview was with the partner of a TB patient, who had also been interviewed. Oh's thesis was exploring the Treaty of Waitangi Principles and the Maori

health strategy through the perspective of tuberculosis care. Her interviews focused on four general areas: health experiences relating to tuberculosis illness and treatment, *Whanau* (extended family) and community responses to tuberculosis, cultural identity and political beliefs (Oh, 2005). A list of Oh's interview questions can be found in appendix III. Additionally, I analyzed interviews with Pacific people conducted by Roannie Ng Shiu, three with pulmonary TB and two with family members of individuals with pulmonary TB. Her thesis, completed in 2006, was interested in the experience of tuberculosis of Pacific peoples in Auckland and Samoa. Specifically, it was interested in the health-seeking behaviours of Pacific TB patients, and how cultural identity, social networks and health beliefs influenced those behaviours. More information on Ng Shiu's interview can be found in appendix IV.

4.3 Data Analysis and Methodology

I had a total of twenty-one interviews for analysis, eighteen individuals with pulmonary TB and three family members or partners (two Pacific people and one Maori person). In Canada, the analysis of the data involved both qualitative and quantitative components. The quantitative data was examined to provide demographic data and additional participant characteristic information. The qualitative interviews were analyzed using an interpretive phenomenological perspective to describe the lived experience of TB for ten potential transmitters (all of whom had smear-positive pulmonary tuberculosis), some of whom would become transmitters and others who would not. Based on the analysis that occurred, visual representations of the social and contextual factors that emerged as relevant for each of the two groups and corresponding summary narratives were developed. They were then compared with each other and with the New Zealand TB experience narratives to identify and compare social determinants of tuberculosis relevant within each context.

The New Zealand interviews were also analyzed from an interpretive phenomenological perspective and were informed by the analysis and emergent themes from Canada. Again, although a comparative piece was not developed between tuberculosis transmitters and non-transmitters in New Zealand, a comparison was conducted between the themes relevant to experiences surrounding TB in New Zealand to the themes determined to be linked to transmission in Canada.

4.3.1 Qualitative Data Analysis.

The qualitative data analysis in both Canada and New Zealand involved a thematic analysis of the interviews using an interpretive phenomenological perspective. The following section describes why phenomenology is an appropriate methodology for this study population. Following that is a description of the history and philosophy of phenomenology and the development of interpretive phenomenology. Additionally, this section includes a discussion on the critiques of phenomenology in current day health research, and why interpretive phenomenology was the best qualitative approach for this project.

4.3.1.1 Phenomenology.

Phenomenology, from the Greek word *phenomenon*, ‘that which appears’ and the Greek word *logos*, “study”, was founded by Edmund Husserl in the early 1900’s (Lindseth & Norberg, 2004). Husserl’s ideas of how science should be conducted gave rise to such an approach and he believed that all experiences, as perceived by the human conscience, had value and should thus be an object of scientific study (Lopez & Willis, 2004). Humans generally go about their daily-lives without critical reflection on their experiences and Husserl believed that a scientific approach was necessary to evaluate the components of these lived experiences. He believed that human understanding of experiences is knowledge in which the meaning of the experience is taken-for-granted. It is shaped by the attitudes and surroundings that one is already familiar with (Lindseth & Norberg, 2004). To truly do phenomenology and study an experience objectively, one must rid oneself of taken-for-granted attitudes and aim for a “phenomenological attitude” in which meaning of an experience is allowed to emerge from *within* the experience itself. Husserl’s phenomenology has become known as descriptive phenomenology in that the goal for researchers utilizing this methodology is to provide an objective description of an experience. A central component of descriptive phenomenology, consistent with the need to allow for a description of the true essence of the phenomenon to emerge from within, is bracketing. Bracketing is the notion that the researcher must free themselves from all prior knowledge on the subject before conducting the research (Lopez & Willis, 2004). Consistent with this idea, some commentators of descriptive phenomenology advocate that a study utilizing this method should not conduct a detailed literature review prior to the study, should not have detailed research questions beyond the desire to describe an experience, and should not be informed by any framework. This is to ensure that the researcher neutralizes their preconceived notions and

achieves transcendental subjectivity. Transcendental subjectivity is the idea that “the impact of the researcher on the inquiry is constantly assessed and biases and preconceptions neutralized, so that they do not influence the object of the study” (Lopez & Willis, 2004). Similar to this is the notion within descriptive phenomenology that there are features of any lived experience, essences, that are common to all those who experience it. Thus, the reality of a phenomenon is considered objective and independent of individual’s history and context. Culture, politics, environment and society and their impact are not considered central to Husserl’s descriptive phenomenology as he believed that humans are free agents and responsible for influencing their own experiences (Lopez & Willis, 2004).

Given my interest in the life experiences of Indigenous tuberculosis patients within the circumstances of their culture, history and social and environmental surroundings, context was important within this study. I required a methodology that though still concerned with describing the lived experience, goes further and allows for the descriptions to be understood within an individual’s life situation and that can be used to provide explanation and interpretation.

4.3.1.2 Interpretive Phenomenology.

Hermeneutic (derived from the Greek word *Hermes* – the Greek god responsible for communicating messages between gods), or interpretive phenomenology, was developed and described by Husserl’s student Martin Heidegger in the early and mid 1900’s. Heidegger challenged some of Husserl’s assumptions within descriptive phenomenology (Lopez & Willis, 2004). Heidegger recognized the importance of an individual’s relationship with their life-world and thus believed an individual’s experiences will be influenced by their world and their circumstances. Heidegger used the term *being-in-the-world* to emphasize that humans, and thus their experiences, cannot be separated from their world. Therefore, it is not the pure objective study of a human’s experience that is the goal with interpretive phenomenology as it is with Husserl’s descriptive phenomenology, but rather what the individual’s description of their experiences implies. The focus of hermeneutic phenomenology is to “illuminat[e] details and seemingly trivial aspects within experiences that may be taken for granted in our lives, with the goal of creating meaning and achieving a sense of understanding” (Lavery, 2003). Consistent with this is the idea that experiences are linked with their social, cultural and political contexts and thus an interpretive inquiry is interested in those situations related to a human and their experience. A literature review and framework are not inappropriate within interpretive inquiry

and can provide guidance in shaping and organizing the understanding of an individual's experience. Bracketing, a critical component of descriptive phenomenology, is not important within Heidegger's interpretive phenomenology. Heidegger believed that a complete neutralization of one's ideas or preconceptions was not possible or even necessary. The researcher's prior knowledge is valuable, is often what guided the researcher to the study in the first place, and "make[s] the inquiry a meaningful-undertaking" (Lopez & Willis, 2004). Interpretive phenomenology is the methodology that guided the thematic analysis of the twenty-one qualitative interviews in this thesis and the presentation of the results.

4.3.1.3 Phenomenology and Indigenous Research.

Given that the participants of this study are all Indigenous, it is important to consider the appropriateness of a phenomenological approach within this population. Although there is not abundant research that discusses this relationship, three researchers have studied the use of phenomenology within Indigenous communities extensively and provide strong commentaries and recommendations on the topic.

G. McCabe believes that phenomenology is an appropriate methodology when working with Aboriginal communities for several reasons (McCabe, April 2008). He believes that phenomenology resembles the traits of a healing intervention. It is not concerned with objectivity or reductionism and it produces positive and concrete results: all important aspects of research conducted with and within Aboriginal communities. Additionally, phenomenology is concerned with understanding experiences within a personal context and as one of the most effective decolonizing research methods, involves continuous collaboration with the research participants. McCabe argues that the use of conventional quantitative research methods within Aboriginal communities has resulted in their mistrust towards scientific research. Phenomenology allows researchers to engage with the participants and the community in which they are researching and as a result, the chance of achieving a more equitable outcome increases. (McCabe, April 2008).

Struthers and Peden-McAlpine (2005) state that phenomenology is compatible when studying within Indigenous communities as it "captures oral history in a holistic and culturally acceptable way". They note that because Indigenous cultures have distinct ways of life, phenomenology as a research methodology allows those values and customs to permeate the research process (Struthers & Peden-McAlpine, 2005). This is harmonious with the world-view of many Indigenous communities. In many Indigenous cultures, a 'fluid line' exists between the

natural and supernatural, material and spiritual, and conscious and unconscious and people can experience multiple realities. These authors note that it is important for researchers to be aware of this different world-view when conducting research with Indigenous communities.

Phenomenological research allows this world view to emerge. Similar to McGabe, Struthers and Peden-McAlpine note that quantitative research is restrictive and places boundaries on the information that can be collected about a community. This type of data collection is not congruent with the Indigenous world view. It is linear; a modality that is not ordinarily embodied in the Indigenous culture (Struthers & Peden-McAlpine, 2005). Phenomenology allows the research participants to describe *their* experiences in *their* way. It allows researchers to collect data in a way that reflects the individuals or community in which the data is being collected from. It “illuminate[s] the words of Indigenous people ... and is able to represent, through written accounts, the lifeworld of Indigenous peoples” (Struthers & Peden-McAlpine, 2005).

Finally, Ellerby (2006), in his doctoral dissertation discusses the use of phenomenology within Indigenous communities. He notes that although it is often used as a research method, it is sometimes questioned. The notion that someone can accurately describe the thoughts, experiences and feelings of another is questioned. The worldview of one community is masked by the interpretive framework of another, the researcher. By trying to understand the Indigenous experience through a non-Indigenous framework, an imposition of world view on another’s experience may occur. Ellerby underscores the importance of a researcher’s interpretive framework for their research project, ensuring it is unimposing, not constrictive, and is consistent with the framework of the community or individuals being studied (Ellerby, 2006).

The above discussion points surrounding phenomenological research are formatted around data collection and a researcher’s first-hand experience with the development of the project, data collection and analysis. This thesis is an analysis of secondary data yet it is still considerate of the aforementioned points important when conducting phenomenological Indigenous research. Importantly, as previously introduced, the analysis is informed by Indigenous frameworks of health. The AFN and NAHO frameworks in Canada, the *Whare Tapa Wha* framework and the Pacific framework are health frameworks that consider the unique viewpoints of the community being studied. Additionally, the data collection tools in Canada were developed in collaboration with the PNCs (previously described in this chapter, p.40). The early results of this study were presented to the PNCs and will again be presented. Throughout

the entirety of the analysis and writing of this thesis, consultation with my supervisors, experienced experts-of-the-field of Indigenous health and tuberculosis occurred. Additionally, this thesis did not rely solely on quantitative data but rather the analysis was centered on qualitative interviews that allowed participants to share their stories and experiences with TB, a central aspect of both phenomenological research and research with Indigenous people. In relation to the New Zealand interviews, the Maori interviews were conducted by a Maori woman and the Pacific interviews by a Samoan woman, both who were aware of importance of culture specific perspectives on research.

4.3.1.4 Critiques of Phenomenology.

Phenomenology is a widely utilized research methodology within health research, with the majority of studies coming from nursing. Advocates for the use of phenomenology in nursing state that it is an appropriate methodology as it can result in applicable solutions within health policy and behaviour (Caelli, 2000). Critics argue however that modern utilization of phenomenology has lost the connection between the philosophical foundations of phenomenology and research methodology and methods. Contemporary philosophers say that phenomenology in nursing is not true to the intent of European phenomenology and that newer versions of phenomenology “serve as an illustration rather than as a critical examination of a phenomena” (Crotty, 1996 in Caelli, 2000).

Throughout my reading of research studies that utilized phenomenology I did notice, in many studies, a trend towards a simple generalized statement on phenomenology as describing a lived experience. Many studies did not make any reference to the philosophical origins and foundations of phenomenology. An example of this is a study by Struthers et al. (2003) that describes the experience of Native peer facilitators in diabetes support groups. The authors note that they are using descriptive phenomenology however they provide no references to Husserl or the philosophy of phenomenology. This is especially apparent in that they make no mention of bracketing. Bracketing is a central component of descriptive phenomenology, and although many researchers believe it is not entirely possible, by not making any mention of the notion, it appears to the reader that the authors were possibly unaware or unfamiliar with the concept. Any study that claims to be a descriptive phenomenological study must at minimum, mention bracketing and comment on or justify why it is not being done despite it being central to the philosophy in which descriptive phenomenology developed.

An example of a positive modern phenomenological study is one by de Witt, Ploeg & Black (2010) which uses interpretive phenomenology to examine the experience of older women living alone with dementia. The authors note their use of one concept within interpretive phenomenology, *lived time*, and briefly discuss its origins in Heidegger. The study is consistent and explicit in connecting the data analysis, thematic development and discussion with their philosophical and phenomenological idea throughout the study. The authors also mention specifically the unique contribution of an interpretive phenomenological perspective on this subject area and what it can provide in terms of nursing policy and social service advancement.

There are numerous interpretations on the applications of phenomenology and many contradict one another. At a conference of phenomenology, over eighteen different forms of phenomenology were identified and discussed. I believe that the greater message of these critiques is the importance of being aware and explicit of the philosophical foundations of the phenomenological methodology utilized. It is important to make those connections throughout the study in the methods and analysis. If an aspect of phenomenology is modified or re-interpreted based on the goals of a study, the researcher must make the reader aware of this, provide justification and discuss how the modifications may differ from the traditional interpretations of phenomenology intended by Husserl and Heidegger.

4.3.1.5 Phenomenology and Secondary Data.

As I came to this study and developed my research goals and questions after data collection had occurred, the research methodology was developed based on the data collection, rather than the traditional form of developing the data collection to fit the methodology. Based on the available data, the types of questions asked in the interviews, and my overall research goal of comparing transmitters and non-transmitters and identifying unique factors of tuberculosis transmission, interpretive phenomenology emerged as the best approach. It allows for an analysis of the lived experience as described and captured by the qualitative interviews and resulted in information that has practical suggestions for future tuberculosis research and prevention.

Although this subject area could be investigated using other qualitative methodologies, interpretive phenomenology allows for the best description of the experience and best answers the research objective of describing the lived experience of tuberculosis patients and examining the social determinants of health associated with transmission or non-transmission using available data. An ethnographic approach, for example, involves observation and integration of

the researcher into the cultural community (van Manen, 1990). The larger project, in which my thesis was placed, was not designed to include an observational component and thus logistically, it was not possible for my thesis to include such an element. I would argue that there are some elements of a case study in this project. Creswell (2009) argues that a case study is not necessarily a methodology but a choice of what to study. It is a strategy of inquiry in which the researcher explores one or more particular events, programs or individuals and the cases are bounded by specific factors. In this study, in Canada, there are two categories of study participants, Alberta Aboriginal people with pulmonary tuberculosis who have transmitted the disease and Alberta Aboriginal people with pulmonary tuberculosis who have not transmitted the disease. The groups are defined by one event - transmission. The New Zealand Maori and Pacific people's experience of TB makes-up a third case group. The case studies define how the participants are organized and the phenomenological inquiry defines how the information of each case is analyzed.

4.3.1.6 Phenomenology and Quantitative Data.

Although not as intensive as initially planned, Canadian survey data capturing patient demographics and characteristics adds information and context to the qualitatively derived experience of TB. However, the quantitative data alone would not provide deep understanding of the lived experience. "Phenomenology is able to portray a holistic picture of human experiences rather than the fragmented account given by quantitative data" (Crazy Bull, 1997 in Struthers & Peden-McAlpine, 2005). For example, the quantitative information highlights the fact that a transmitter may be alcohol dependent, but the qualitative description and the phenomenological analysis provides insight into how alcohol use is a daily factor of an individual's life and how it affects other aspects of life, including health. The quantitative data complements the qualitative information, but alone, I believe it would not provide enough information to address the objective. In this study, the quantitative information can inform of a relationship or correlation, but it is the qualitative information that describes why that relationship exists and how it affects daily life.

4.4 Data Analysis Techniques

The following section outlines the specific data analysis steps that took place. The first section outlines the data analysis strategy in Canada. The specific steps in the New Zealand data

analysis are then described and the section concludes with the approach to considering both data sets together.

4.4.1 Canadian Data Analysis.

As mentioned above, I was not involved in the interview collection or transcription process. After dividing my Alberta study participants into transmitters and non-transmitters based on the point system (described on p.45-46), I accessed the interviews. To keep the comparison as authentic as possible between the two groups I first read the male transmitters followed by the male non-transmitters and then the female transmitters followed by the female non-transmitters. The thematic analysis considers the differences between the male and female participants within and between categories of transmission. I analyzed the seven male interviews first and the data analysis steps were as follows:

1. I did an initial read through of each interview to gain an understanding of the interview process and the description of the experiences.
2. I then did a second read-through and began coding the transcripts. I highlighted phrases, words and experiences that appeared relevant to the participant's experience of tuberculosis. Identification of relevant phrases was informed by the information that emerged from the literature review, by the general social determinants of health framework and the AFN and NAHO health frameworks, and from the participant's experiences and phrases or words that were repeated or emphasized and that appeared important to the overall TB experience. Additionally, I highlighted information from the interviews that required clarification. Clarification was then obtained through discussions with my supervisor and listening to the audio recordings.
3. After the first coding I re-read the seven interviews and re-coded. This resulted in some re-organization of phrases and words, and merging or splitting codes.
4. Finally, I did a fourth read through of the seven male interviews and organized the codes and participant quotes into different themes to describe their experience of TB, looking for differences in the transmitter and non-transmitter groups. The development of the themes and the thematic analysis is described in the next section. This was done by creating documents in which the theme served as the title of the document and the participant descriptions and quotes were placed into the appropriate theme.
5. I then repeated the process with the three female interviews.

6. Initially, I did not have access to the Canadian interview recordings. I did obtain them and listened to the recordings after I completed the fourth read through and final coding and organization as previously described. Although accessing the audio recordings did not substantially change any of my codes or themes, listening to the interviews helped clarify certain questions I had previously.

7. I created two visual representations, one that illustrates the factors associated with the experience of tuberculosis for the five participants with transmission events and one for the five non-transmitters. The visual representations also explored the connections between each factor and the pathways with how they may be associated with increased transmission.

8. Finally, I created summary narratives that captured the experience of having tuberculosis for both groups. The narratives complemented the visual representations in detailing and expanding the context and connections between the factors within the visual representations.

4.4.2 New Zealand Data Analysis.

In New Zealand, the logistical process of data analysis was similar to the process in Canada.

1. I met with Moana Oh and Roannie Ng Shiu, obtained permission to access their interviews, and posed questions to both regarding their experiences.

2. I began with the six Maori interviews. I read through each interview once (division did not occur based on sex as occurred in Canada), without coding, to gain an understanding of the interview process and the description of the experiences.

3. I did a second read through of the Maori interviews and coded the information. The codes were developed from the Canadian TB experience code list, with new codes developed to capture information emerging from the interviews. Additionally, the Maori framework of health informed the coding of interviews, similar to how the AFN and NAHO frameworks informed the analysis of the Canadian Aboriginal interviews.

4. I did a third read through of the Maori interviews. This resulted in some re-organization of phrases and words. Finally, I organized the codes into themes, which again were based on information from the Canadian analysis, the Maori health framework and the interviews themselves. This was done by creating documents in which the theme served as the title of the document and the participant descriptions and quotes were placed into the appropriate theme.

5. I did one read through of the five Pacific interviews. Due to the decreased length and detail of these interviews I also began coding during this time. Again, the codes were developed based on the Canadian and Maori analysis codes, unique ideas from the Pacific interviews, and awareness of the Pacific framework of health.
6. I did a second read through of the Pacific interviews for re-coding and organization. Finally, I organized the codes into thematic analysis similar to the process described for both the Maori and Canadian codes.
7. In New Zealand, I did not have access to the original audio recordings. However, I did contact Oh and met with her a second time in which I asked her clarifying questions regarding her interview participants.
8. Similar to the Canadian data, I created a visual representation that illustrated the factors associated with the experience of tuberculosis for the Maori and Pacific people. The visual representations also explored the connections between each factor and the mechanisms with how they may potentially be associated with increased transmission.
9. Finally, I created a summary narrative that captured the experience of having tuberculosis for the Maori and Pacific people. The narrative complemented the visual representation in detailing and expanding the context and connections between the factors within the visual representation.
10. I created another document that compared the factors determined to be associated with transmission in Canada with the New Zealand experience of TB.

4.4.3 Thematic Analysis.

The themes that emerged from the coding process and interviews were formed from the participant's descriptions of their experience. As I was reading the interviews and coding I noticed categories emerging and it was a process of organization of compiling the codes into over-arching themes.

Van Manen (1990) describes phenomenological themes as the "structures of the experience" and notes that with thematic analysis "[the researcher tries] to unearth something 'telling,' something, 'meaningful,' something 'thematic' in the various experiential accounts – we work at mining meaning from them". Themes are not objects or generalizations; themes are intransitive or like "knots in the web of our experiences". It is themes that have "phenomenological power" and allow us to proceed with descriptions of an experience (van Manen, 1990). The themes represent the commonalities in an experience and allow a researcher

to “illuminate the phenomenon in a way in which they are not destroyed, distorted, decontextualized, trivialized, or sentimentalized” (Benner, 1985).

In relation to tuberculosis transmission, the themes that emerged that were of most interest to this project were surrounding life experiences prior to TB diagnosis including substance use, financial circumstances, family support and patient delayed diagnosis. Themes describing the hospital experience including health system delayed diagnosis, treatment experience and relationship with hospital staff were also of interest.

At this stage of the data analysis, my steps have followed closely to recommended phenomenological analytical steps that are both described in the literature as well as followed by other phenomenological researchers. Two areas of departure in my study are related to the audio-recordings and the return of the thematic analysis to the participants. Phenomenological researchers recommend listening to the audio-recordings in the early stages of the analysis procedure as a means of clarifying the transcription and noting the participant’s tone and silences. Lavery notes that it is important to not only pay attention to what is said, but also what is said “between-the-lines” (Lavery, 2003). The silences may be an individual attempting to gather their thoughts, but the silences may also provide insight into the individual’s experience and it is in these silences where “one may find the taken for granted or the self-evident” (Lavery, 2003). The silences, the point at which the silences occur and the way in which the participants react after silences may provide additional information on their experiences. However, I did not have access to the Alberta audio-recordings at the onset of the data analysis stage or the audio-recordings of the New Zealand interviews at any time. I was able to access the Alberta audio recordings and listen to many of the participant’s voices later in the analytical stage. During this stage, I was able to clarify questions from the transcript as well as pay attention to the tone of the participant. For example, based on the word-choice of many participants, after reading just the transcript of their interview I perceived their tone to be angry. By accessing the audio-files I was able to evaluate this interpretation and clarify the relationship between word-choice and tone for each participant. Another recommendation within phenomenological research is to return a copy of the thematic analysis and the researcher’s interpretation and organization of the participant’s description to the participant for clarification and validation. However, given that the interviews were conducted by other researchers and took place years ago, it was not possible for me to return to the participants in this study. This point is

addressed in that my interpretations and thematic analysis were discussed with my supervisors and have been presented in its early stages to the PNC in Canada, and will be again.

4.4.4 Visual Representations.

The next step in the analysis process was to organize and visually represent the themes that emerged from the analysis of the interviews. These representations highlighted the relevant social factors in the experience with tuberculosis and outlined the connectivity between the factors, as the information emerged from the interviews. Additionally, the visual representations sought to explore mechanisms with how the factors that emerged as being relevant to the overall experience with tuberculosis may relate to disease transmission. Three visual representations were created, one for the five Aboriginal people from Canada with tuberculosis who transmitted the disease, one for the five Aboriginal people from Canada with tuberculosis who had few or no transmission of the disease, and one for the Maori and Pacific people's experience of TB in New Zealand. The goal was to create pictorial representations of how themes were more relevant or less relevant for one group compared to others.

4.4.5 Narratives.

After developing the visual representations of the themes representing the important factors of tuberculosis transmission and non-transmission based on the participant's experiences, I developed a summary narrative for each category. This textual representation of experiences used participant quotes and themes to create stories of TB experience for Aboriginal people in Alberta with tuberculosis who were identified as transmitting the disease, Aboriginal people in Alberta with tuberculosis who were identified as not transmitting the disease, and for Maori and Pacific people living in New Zealand.

4.5 Quantitative Data Analysis

The questions of the quantitative questionnaire were grouped into four categories focused on *how* tuberculosis transmission occurs: (i) diagnostic delay, (ii) environmental circumstances, (iii) number and susceptibility of contacts and (iv) program malfunction. The initial plan was to conduct logistic regression with the quantitative questionnaire data as a means of determining predictors of tuberculosis transmission. Logistic regression is used to describe the relationship between an outcome and independent predictor variables (Hosmer & Lemeshow, 2000). In my analysis, the outcome is dichotomous; an individual is either a transmitter or a non-transmitter.

The predictor variables were to include several variables collected from the quantitative questionnaires including socioeconomic status, geography, ethnicity and questions surrounding transmission.

However, with only ten participants that could be sub-divided by transmission events during the time this research was taking place, logistic regression was not possible. The quantitative data was therefore used to supplement the information from the qualitative interviews. The survey responses provided demographic and characteristic data about each participant and were used in conjunction with the qualitative information to create and compare the experiences between the transmitter and non-transmitter groups. The results section of this thesis includes tables describing the information obtained from the quantitative surveys as well as demographic data from the New Zealand cases.

4.6 Summary

This chapter describes the data collection and analytical techniques that occurred in both Canada and New Zealand as a means of addressing the research objectives. In Canada, to achieve the research goal of identifying unique factors of tuberculosis transmission, study participants were divided into transmitter and non-transmitter groups through a ranking system using both molecular and epidemiological techniques. In New Zealand, this comparison was not possible, but interviews from Maori and Pacific TB patients were accessed. In both contexts, interviews were analyzed using an interpretive phenomenological perspective informed by Indigenous health frameworks. The themes that were extrapolated from the qualitative interviews were used to develop visual representations and summary narratives describing the experience of being a tuberculosis transmitter or a tuberculosis non-transmitter. These narratives were then compared and a number of factors of transmission were identified. Additionally, the Canadian transmission-associated factors were compared to the New Zealand context to determine their relevance. Although there are critics of the use of phenomenology in nursing and public health research, interpretive phenomenology was the most appropriate methodology for this research project based on the research goals and available data. The following section of this thesis outlines the results of the study and includes the visual representations and narratives that were developed.

Chapter Five: Results

The following chapter outlines the results from the interpretive phenomenological analysis of both the Canadian and New Zealand qualitative interviews. Additionally, information from the quantitative questionnaires is described here and included in the textual descriptions of the tuberculosis experience. The documents contained in the results section include visual representations, a textual description of the experience of a Canadian TB transmitter or non-transmitter and the experience of having TB in New Zealand. The narratives that were created based on the analysis of both the Canadian interviews and New Zealand interviews are included in this section. Finally, the results section includes a comparison of the Canadian transmitter and non-transmitter data and a comparison of the Canadian transmitter data with the New Zealand information. The subsequent chapter, the discussion, expands on the findings of the factors associated with transmission and explores other research on these factors and how they ultimately may lead to increased TB transmission.

5.1 Demographic Information of Alberta Transmitter and Non-Transmitter Groups

Within the transmitter groups, there was one female and four males. The average number of close contacts for the transmitters was 42.2. Within the non-transmitter group there were two females and three males who had, on average, twelve close contacts. The transmitter group had a range of transmission points from seven to thirty-four (average of 18.2) while the non-transmitter group has a range of transmission points from zero to three (average 0.8).

Table 5.1 (p.63) describes the points for each of the five Alberta transmitters and table 5.2 (p.63) describes the points for each non-transmitter. Individuals were given four points if they had a close contact that became a secondary case, confirmed by matching DNA fingerprints and social relationships, and were given three points if close contact became a secondary case but was not confirmed by matching DNA fingerprints of the *M. tuberculosis* isolate. They were given two points if a close contact was a tuberculin converter and one point if a close contact was a recent positive. A more detailed description of how the points were calculated and assigned is given in the methodology section (chapter four, p.44-46).

Additional information from the cases was obtained from the quantitative questionnaire. Table 5.3 (p.64) summarizes the results categorized based on transmitters or non-transmitters. There are three factors that emerged as being more significant in the transmitter group, substance

use, patient-delay-in-seeking-treatment, and number of contacts (as indicated by housing density in this table). These are highlighted in table 5.3 (p.64).

Table 5.1: Description of the transmission points for the five Alberta transmitters.

Participant	Gender	Total Close Contacts	Secondary cases (molecular confirmation)	Secondary cases (no molecular confirmation)	Tuberculin Converters	Recent Positive TST	Total points
Catherine	Female	74	2	1	8	7	34
Robert	Male	15	2	3	0	3	20
Joseph	Male	37	0	0	4	7	15
David	Male	77	1	1	2	4	15
Adam	Male	8	1	0	1	1	7

Table 5.2: Description of the transmission points for the five Alberta non-transmitters.

Participant	Gender	Total Close Contacts	Secondary cases (molecular confirmation)	Secondary cases (no molecular confirmation)	Tuberculin Converters	Recent Positive TST	Total points
Rebecca	Female	16	0	0	1	1	3
Nathaniel	Male	15	0	0	0	1	1
Rosemary	Female	6	0	0	0	0	0
Aiden	Male	22	0	0	0	0	0
Mark	Male	2	0	0	0	0	0

Table 5.3: Additional characteristic information for the Alberta transmitter and non-transmitter groups. This information was obtained from the quantitative questionnaires that each participant completed. The highlighted fields indicate the characteristics that emerged as important potential points of distinction between the transmitter and non-transmitter groups.

	Transmitters	Non-Transmitters
Marital Status	Single – 3 Common Law – 2	Single – 3 Divorced – 1 Married – 1
Aboriginal Status	Treaty Indian – 4 Métis – 1	Treaty Indian – 3 Métis – 2
Highest level of education	Some High school – 4 Non-Trade college – 1	Some High school – 3 High school diploma – 1 Trade college – 1
Working until got sick	Yes – 3 No – 2	Yes – 1 No – 4
TB HEALTH		
Time between symptoms and diagnosis (weeks)	4, 12, 20, 32, 36 (avg. = 20.8)	4, 4, 12, 14, 16 (avg. = 10)
First time sick with TB	Yes – 5	Yes – 4 No – 1
Knowledge of contact with someone with TB	Yes – 2 No – 3	Yes – 3 No – 2
On immunosuppressants	No – 5	No – 5
Other health issues	No – 4 Yes – 1 (HIV/AIDS)	No – 3 Yes – 2 (Type II diabetes non-insulin, Type II diabetes insulin & asthma)
Symptoms	Cough – 5 Night sweats – 4 Weight loss – 4 Lost voice – 1 Sore back – 1 Congestion – 1 Fever – 2 Fatigue – 1 Chest pain – 1 Weakness – 2 Shortness breath – 1	Cough – 4 Night sweats – 3 Weight loss – 3 Congestion – 1 Fever – 3 Chest pain – 2 Chills – 1 Sore stomach – 1 Diarrhea – 1
SUBSTANCE USE		
Drink alcohol	Yes – 5	Yes – 3 No – 2 (previously yes)

Drinks per week (identified as alcohol dependent)⁸	0.5 (yes)⁹, 9 (no), 12 (no), 207 (yes), 237 (yes)	0.5 (no), 25 (yes), 69 (no)
Smoker at diagnosis	Yes – 3 No – 2	Yes – 2 No – 3 (2 previously)
Injection drug user	No – 5	No – 5
Non-injection drug user	Yes – 4 No – 1 (but previous user)	Yes – 2 No – 3 (3 never)
HEALTH CARE		
First see with health problems	Physician – 3 Relative – 2	Physician – 3 No one – 1 Unknown - 1
Who did you first see about TB symptoms	Physician – 4 Nurse – 1	Physician – 4 Unknown – 1
Where do you first see doctor?	Hospital (off-reserve) – 1 Clinic (off-reserve) – 4	Clinic (off-reserve) – 1 Unknown – 1
Family doctor	Yes – 3 No – 2	Yes – 2 No – 3
See traditional healer	No – 2 Yes – 3 (not for TB)	No – 4 Unknown – 1
COMMUNITY		
Adequate access to health care in community	Yes – 4 No -1	Yes – 5
Community health centre?	Yes – 4 Unknown – 1	Yes – 2 Unknown – 3
Community type	Rural (on-reserve) – 4 Urban – 1	Rural (on –reserve) – 2 Urban – 3
JAIL		
Jail time	Yes – 2 No – 1 Unknown – 2	Yes – 1 No – 3 Unknown – 1
HOUSING		
Accommodations	Shared – 1 Homeless – 1 Relative’s house or condo – 2 Band-owned ¹⁰ house or	Shared – 1 Band-owned house or condo – 1 Unknown – 3

⁸ Alcohol dependency was determined by the survey analysts based on whether an individual responded yes to at least three of six categories within the alcohol section of the survey.

⁹ These columns of the table are organized to represent the alcohol information of the five individuals in the transmitter group that self-identified as consuming alcohol. For example, individual one identified as having 0.5 drinks per week and based on the same individual’s responses to the six relevant questions in the survey, was identified as being alcohol dependent. For those in the non-transmitter group, only three individuals self-identified as drinking alcohol and accordingly there are three groupings in the row – drinks per week (identified as alcohol dependent).

	condo – 1	
# of people in house & # rooms in house (housing density)¹¹	4 & 6 (0.67), 18 & 8 (2.25), 19 & 8 (2.4) N/A – 2	3 & 5 (0.6), 4 & 6 (0.67), 1 & 1 (1), 15 & 7 (2.14) N/A - 1
Pets in house	No – 3 Yes – 1 N/A – 1	No – 1 Yes – 2 N/A – 1 Unknown – 1
Smokers inside	No – 1 Yes – 3 N/A – 1	Yes – 4 Unknown – 1
Mould	No – 4 N/A – 1	No – 4 Unknown – 1
Air ventilation	Very good – 1 Good – 1 Fair – 2 Very poor – 1	Very good – 2 Good – 1 Fair – 1 Unknown – 1

5.2. Alberta Visual Representations

Figure 5.1 (p.67) and 5.2 (p.75) are the visual representations illustrating the themes that emerged of importance relating to the experience of tuberculosis for the transmission group and non-transmission group for the Alberta participants. The red text indicates the three factors that were identified as being more important to transmission and distinct in magnitude between the transmitter and non-transmitter groups. The different text and arrow size identifies the relative importance of each factor as it pertains to each group. In figure 5.2 (p.75), the purple text represents the factors that were identified as being more important for the non-transmitter group.

5.3 Textual Description of Results of Qualitative Interview Analysis

The following text complements the visual representations and describes the factors that emerged from the analysis of the qualitative interviews. The descriptions also include information from the quantitative questionnaires.

¹⁰ Refers to groups of people who share common ancestry, traditions and values, and who signed treaties with the Crown. Today, most bands prefer to be known as First Nations. A band-owned house is one that is built, managed and owned by the band on reserve (International Housing Coalition, n.d).

¹¹ These columns of the table are organized to represent the housing information for the five individuals in the transmitter group (and the non-transmitter group in the non-transmitter column to the right). For example, individual one identified four people living in the same house as them, identified the house as having six rooms and as a result, the housing density was calculated to be 0.67 [4 & 6 (0.67)]. Because two individuals identified as living in shared accommodations, their information was not available and the housing density could not be calculated.

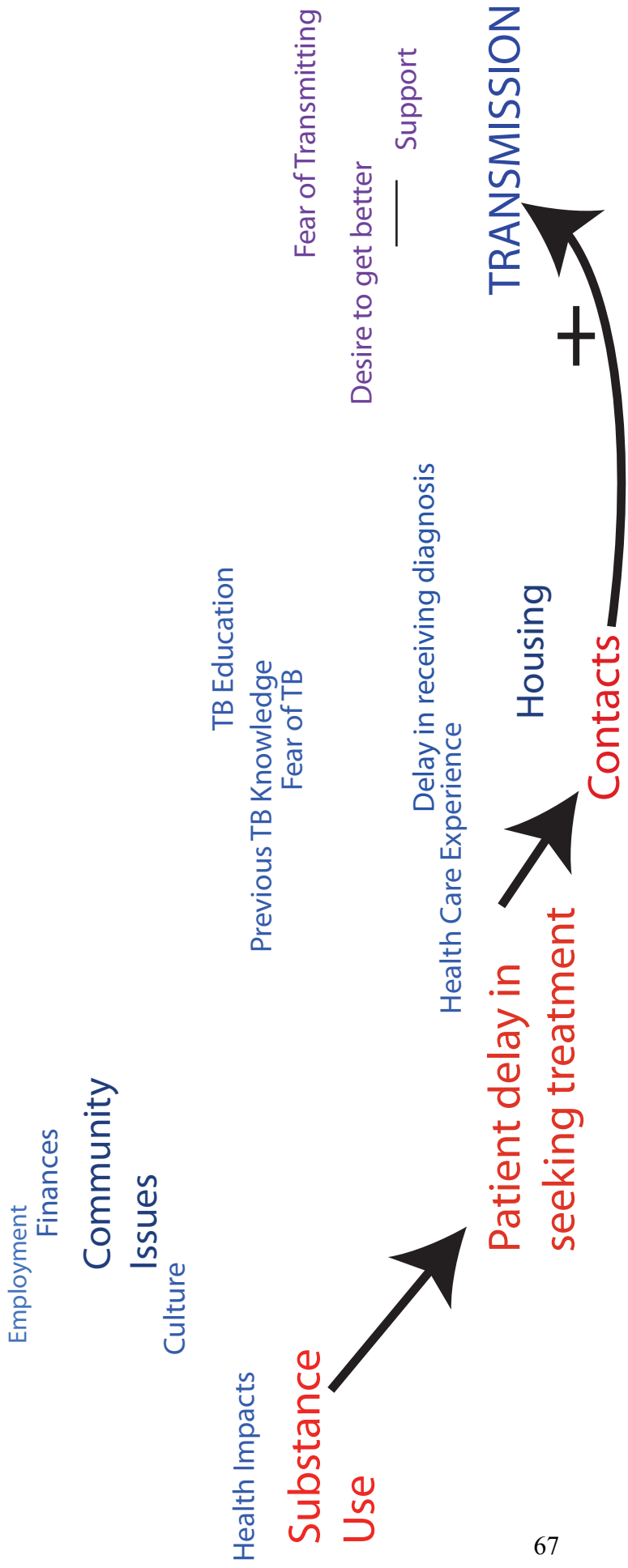


Figure 5.1: Visual representation of the Alberta transmitter group experience of TB.

5.3.1 Alberta Transmitter Group.

There were five individuals in the transmitter group, four males and one female. The mean age at the time of diagnosis was thirty-five. All are of Aboriginal ancestry (four status Indian and one Métis) and three were single while two were in common law relationships.

Education and Finance

Four of the individuals did not have high school diplomas, while one had completed a non-trade college program. Only two of the transmitters were working up until they got sick. Most of the transmitters faced financial struggles. Robert noted how when he was working and making lots of money he would spend it on alcohol and gambling but at the time of his diagnosis he felt he could not afford to stay in the city near the doctor and receive treatment. David described himself as “broke” and had to rely on his son to pay for the antibiotics and Tylenol 3’s that were initially prescribed to him. Joseph described having to often sleep on the streets or at shelters and Catherine noted that when there is money it is spent on beer or bingo.

Contacts and Relationships

The transmitters had an average of forty-two close contacts each (between eight and seventy-seven). Three of the transmitters noted that they lived with multiple family members or household occupants. Catherine noted that she worked in a daycare and that “me and kids mix”. Only David noted that he liked to be alone. All of the male transmitters described at least one person who provided support. The female transmitter talked the most about the support of her family and how her husband feels lost without her while she is in the hospital, “Husband came to visit, but he doesn’t like it, he feels lost without me”.

Housing

None of the transmitters were known to live in an accommodation with a pet or in an accommodation with mould. One of the transmitters rated the air quality as fair, one as good, one as very good and one as very poor. One of the transmitters was homeless, one lived in shared accommodations, one in a relative’s house or condominium and one in a band-owned house or condominium.

*Patient-delay-in-seeking-treatment and Substance Use*¹²

The transmitters had a delay in tuberculosis diagnosis¹³ between four and thirty-six weeks (average of twenty weeks, the transmitter with the shortest delay of four weeks was the female transmitter). Many of the transmitters initially attributed their TB symptoms to alcohol or smoking. All of the transmitters drank alcohol at their time of diagnosis and four of them were identified as being alcohol dependent, based on their responses to six questions in the survey. Three of the five transmitters were smokers at the time of diagnosis and all were either using non-injection drugs at the time of diagnosis or had previously used non-injection drugs. Adam noted that there was “too much drinking to notice being sick” and that he “didn’t even notice the sickness was with me”.

When I got out [of jail] I was sick when I went home and I started drinking with it. You know I drank every day almost so I didn’t even notice that, that it was still with me. (Adam).

Adam was kicked out of a town for his excessive alcohol use and noted that he could not utilize the health services immediately. Additionally, Adam noted that the sickness could have been with him for a long time but he was smoking a lot and may not have noticed.

Like I was saying I probably would have lived with me for the last few years, you know, because I don’t know. I was smoking cigarettes. I smoked pot. (Adam).

Robert attributed his symptoms to drinking but he believed that the sickness would eventually go away and one of his solutions was to change his drink of choice.

¹² The term substance use is used in this thesis instead of substance abuse. Although many interviewees self-described their issues and experiences surrounding alcohol use in relation to substance use and substance problems, it was decided that the more neutral term use would be used. Instead of labelling the issues as substance abuse, the participant quotes and experiences lend themselves to such understanding, interpretation and conclusions.

¹³ On the survey, individuals were asked to state the length of time between the onset of their symptoms and their TB diagnosis (appendix I).

Yah, I know, like I, like I said for a while there I thought it was whiskey and then after that I was kinda like “Well fuck, whatever.” I, I thought I’d change whiskies. (Robert).

Robert also initially attributed his symptoms to his drug use. Additionally, he was concerned that other people, such as employers, would question whether his TB symptoms were due to his drug-use and alcohol use.

[I]f I’m sick, I’m gonna call in sick [and] they’re gonna think that it’s just from drinking or something you know (Robert).

He commented on the connection between health and alcohol and noted that other people told him that if he wanted to get better he would have to quit drinking. David saves up his money to buy alcohol and he believes the “alcohol gotta save me”. He talks about how Natives¹⁴ drink anything with alcohol in it.

We drink hairspray, we drink Listerine, Lysol anything that’s alcohol in it. (David describing how he believes some Native people are addicted to alcohol and will drink anything with alcohol in it).

The female transmitter Catherine noted that when she has money she goes to get beer. Joseph noted that he had been caught up in the wrong-crowd and was using drugs and having an unhealthy lifestyle.

Those in the transmitter group also commented on community issues surrounding drugs and alcohol. They noted that alcohol and drugs have led to violence and family breakdowns and that people don’t care about their health – they drink a lot and they are sick but they do not care. They believe that alcohol and drugs in the community are the reason that kids do not listen anymore.

¹⁴ A term often used to describe or identify an Aboriginal person, specifically an American Indian or First Nation person.

There's nobody can stop this what's happening now, nobody can change it. A lot of elders will tell you elder people it's too late there's nothing you can do. (David).

Other Diagnoses

Individuals in the transmitter group often received other diagnoses initially before ultimately receiving a diagnosis of TB and appropriate medication. Robert was initially diagnosed with pneumonia and bronchitis. He was given other medication for those diagnoses that did not work. He also described a negative relationship with some doctors. He felt that he visited the doctor on several occasions because he was not getting better. In one incident, the ER doctor told him to go see his family doctor and then his family physician told him to go to the ER.

He [emergency room doctor] said "You should go see your family doctor. This is for emergencies." I said "Doesn't this sound like an emergency? It took me three times to come in here and you guys couldn't prescribe anything right for me being better?" I said "There's something going on here then you know". I said "First you guys told me it was bronchitis, now it's pneumonia. (Robert describing his experience with his doctors).

Additionally, Robert described an occasion in which he went to see a doctor and the doctor just prescribed him pain medication. Throughout the appointment, Robert felt that the doctor did not consider his symptoms and only prescribed medication because the doctor felt that this was what he, the patient, wanted. Robert was also not diagnosed with TB initially. He made several trips to the doctor and he often felt that the doctors did not take him seriously. He was initially given Tylenol 3 for the pain. He also felt that the community nurse knew that he was feeling sick but "maybe she thought I was bullshitting". He did note that once it was discovered he had TB he was admitted to the hospital immediately. David was initially diagnosed with pneumonia and on a visit to the ER for shortness of breath was given Tylenol 3. Catherine was initially diagnosed with pneumonia and given antibiotics that did not end up working. On her second visit to the doctor, she told the doctor she was in contact with someone with TB, even though she was not, so that the doctor would test her for TB.

Previous Knowledge of TB

In general, those in the transmitter group noted they had no previous knowledge of TB. Some of the transmitters were aware of the history of TB in the Aboriginal communities and commented on how it affected Aboriginal people more than White people. David says that he did not know what TB was until 'today' (date-of-interview) and that if he had known more about it he would have asked about it sooner when he got sick.

TB, I don't know. Til, til today I don't even know what it means. All we know is the word TB. They never taught us. Told us what it meaning of.
(David).

Catherine stated that she knew nothing about it, although after an initial other diagnosis, she told her doctor she had been in contact with someone with TB, even though she had not, so that the doctor would check her for TB. Although the transmitters stated that they did not have much previous knowledge of TB, throughout the interview they all showed some knowledge of TB related information but it is possible that this information was learned after being diagnosed with the disease in the hospital and prior to the interview. Both Adam and David noted that in relation to TB education, it was hard to get people in the community to talk about the disease. They described that in their community no one cares and they do not talk about the disease with one another.

Fear of TB and TB Transmission

Three of the transmitters talked about fear of TB. Adam described how his sister was a bit fearful when he was diagnosed with TB as her husband had been sick with TB previously and spent time in the hospital. David believed that because TB is not talked about in school, his children would be teased about it if they were identified as to have TB.

Unless they start talking about it in school. They'll probably get a bad name to themself and probably kids will tease them. (David).

Catherine believes that people are scared of her now and she described how one lady was panicking when she realized Catherine had TB and had been working with her children in the daycare.

Health Care

For all five of the transmitters, this was their first time sick with TB and only two of them were aware of past contact with someone who had TB. Only one of the transmitters had another ongoing health problem (HIV/AIDS). Three of the five of them had a regular family doctor while four believed they had adequate access to health care in their community. Three of the transmitters had seen a traditional healer before, but none had seen one in relation to their TB.

Recovery and the Future

Four of the transmitters commented on wanting to get better and recover from TB. They wanted to know what was wrong with them and get better. Joseph commented on how he wanted to quit his bad habits and move on from his past and he hoped that the upcoming birth of his child would provide motivation. Adam wants to cure his sickness and be active again and David does not want to die. He trusts the doctors and states that he would stay in the hospital until they say he is better. He tries to control his coughing as he does not want to “help the sickness”.

TB Transmission

Catherine also described how she was fearful of transmitting the disease to her children. She also believed that TB continues to be transmitted and be relevant because people do not care about their health – they are drinking a lot and they are sick but they do not care. David also worried about transmitting to children and he believes that it should be a priority for children to be checked. He thinks they will not because people, including their parents, do not care. Adam was also worried about the kids in his house and passing the disease to them. Robert related TB to air pollution, poor environment, increased number of people around and diet.

Culture and History

Four of the transmitters provided at least some information about culture and tradition and the loss of their culture. Robert connected the loss of his community’s land and the change and destruction that followed with poor health and increased alcohol use in his community.

To me using a skidoo a long time ago just to go out in the bush and, and hunt and put out snares and traps... like there’s no money in furs and stuff

like that... just the, the fun, the game, the doing it... kept you go, kept me away from drinking and stuff like... Now I don't do it as much from, but fuck I tell you man, I drink, I drink a lot more than I, you know. I don't do that much other things than that 'cause I mean that was taken, that taken away from me now. (Robert describing that changes to his land means he cannot go out and hunt anymore or work in the bush and that has resulted in increased drinking).

Throughout his interview, he reflected on his past when he was able to hunt in the bush and expressed disappointment and anger towards the loss of land, the changes that occurred, and the government. He was angry that he could not do anything to prevent it. He also commented on the medicine man and that sickness may be someone putting bad medicine on you – he was somewhat reluctant to talk about it with interviewer and although she offered to turn off the recorder, he ultimately continues on talking about it and being recorded. David prays to the Creator to get better and is interested in traditional medicine. He also comments on the violence against the environment and how life is now all about money, power and drugs. He compares the current wars that the United States are involved in to the “Native situation” in Saskatchewan and reflects on the old days and how things were better when there were family values and before there was alcohol. He says that drugs and alcohol are taking over and that the Elders say it is too late to do anything. Catherine also prays when she is sick for strength and smudges¹⁵ as a way to get better. Joseph has participated in round dances and he notes that it was a good way to get away from his life situation.

5.3.2 Alberta Non-Transmitter Group

There were three males and two females in the non-transmitter group. The mean age is forty-two. All are of Aboriginal ancestry, three are status Indians and two are Métis. One non-transmitter is married, one is divorced and three are single.

Education and Finance

Three of the individuals in the non-transmitter group do not have a high school diploma. One has a high school diploma and one has completed a trade college. Only one of the non-

¹⁵ A smudge ceremony is a cultural practice that involves the burning of sweat grass or sage as a way of cleansing or connecting with others present and with others who are not present, including the spiritual world and the Creator (Neumann et al., 2000).

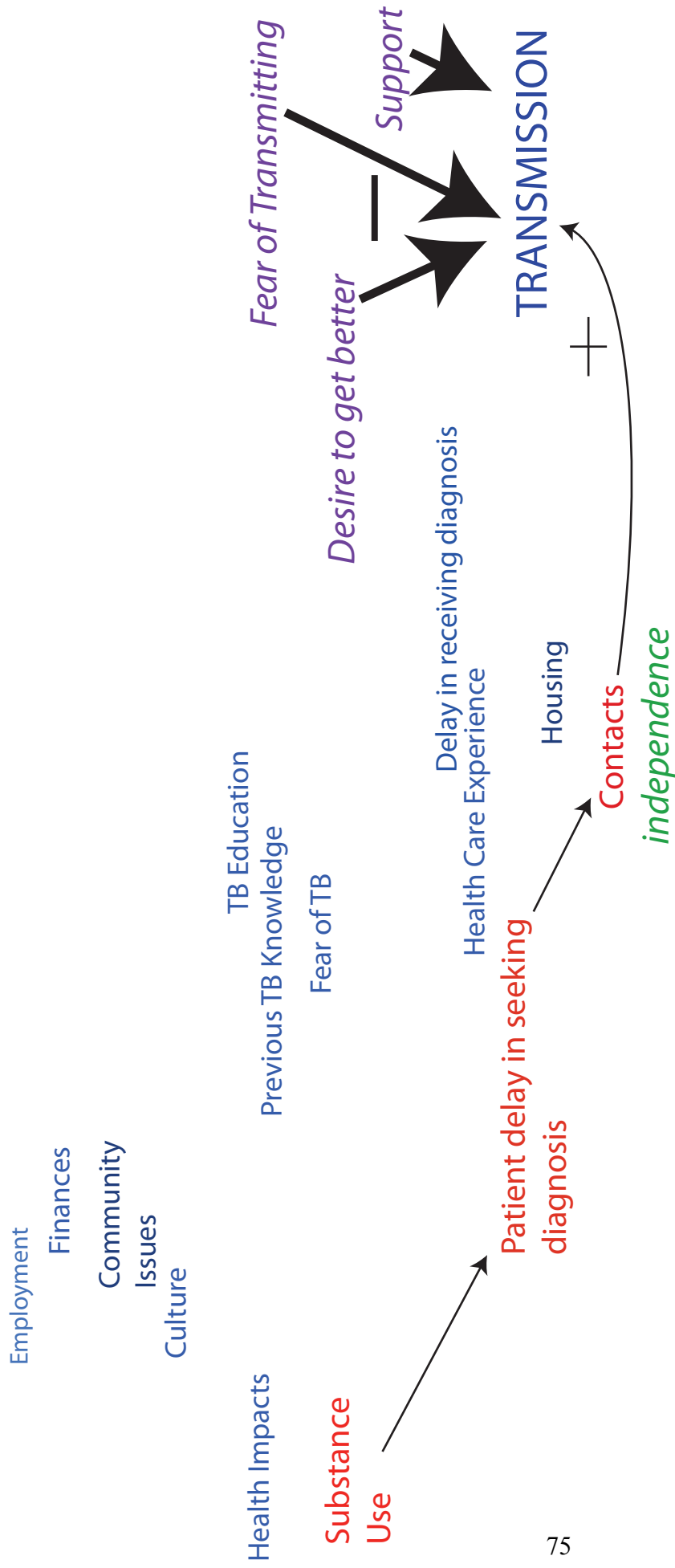


Figure 5.2: Visual representation of the Alberta non-transmitter group experience of TB

transmitters was in paid employment prior to becoming sick with TB. Only two of the individuals in the non-transmitter group commented on financial issues. Mark has been homeless and although he likes Alberta, he finds it expensive to live there. However, he receives Residential compensation money¹⁶ and believes that will enable him to find a place to stay. Nathaniel is on disability support. Rebecca noted that when she became sick she did not have a car and had to call the paramedics to check on her health and then take her to the hospital.

Contacts and Relationships

The individuals in the non-transmitter group had an average of 12.2 close contacts. Two talked about enjoying being on their own. Mark said he did not have much of a social life and that he tends to be on his own. He has very few friends and is independent. He does not keep in contact with his family and says that he does not have a lot of support. Nathaniel also likes to be on his own. He lives in a rooming house in Edmonton and has only one friend in Edmonton. He does believe that he has some support from his family. Aiden also said that when he is sick he does not like to go see anyone. Only the two females describe the importance of their family and family support, explaining that their lives revolve around their families, especially their kids.

My family [who Rosemary turns to for healing]. They are always there to support me. My life revolves around my family. I try to make it easier for them. I don't want to pass on this disease... (Rosemary describing how she turns to her family for healing and how they give her support). During her interview, the note-taking had to stop at one point as the individual became emotional. The participant was feeling quite overwhelmed about the way she has tried to protect her family and that she is now forced to be away from them and away from her life.

Housing

All five individuals live in different types of accommodations. One lives in an owned house or condominium, one in a band owned house or condominium, one in an apartment or hotel, one in a shared accommodation and one in an accommodation classified as other (based on

¹⁶ Former residential school students are eligible to receive monetary recognition and compensation for their experiences through the Common Experience payment, a component of the Indian Residential Schools Settlement Agreement (Service Canada).

questionnaire). Two live in accommodations with pets. Three of the individuals rated the air quality of their accommodations as very good, while the other two rated it as good and fair. None of the individuals in the non-transmitter group indicated that they live in accommodations with mould.

Patient-delay-in-seeking-treatment and Substance Use

The individuals in the non-transmitter group had delayed TB diagnosis¹⁷ of between four to sixteen weeks (mean 10.4 weeks). Aiden said that when he is sick he likes to “cough-it-out” and just let it go until it gets better. Mark also said that when he is sick he likes to take care of himself and “stick-it-out” himself until he is better. Three of the individuals drank alcohol at the time of the diagnosis and one was considered to be alcohol dependent, based on responses to six questions in the survey. Two non-transmitters were current non-intravenous drug users and of the three that were not current users, none had been past users of non-intravenous drugs. Two non-transmitters were smoking until diagnosis and of the three that were not currently smoking, two had been previous smokers. Aiden noted that a typical day for him included going to the liquor store and Mark said that sometimes he and his family were too drunk to care what they said to one another.

We don't really talk to each other that much. Sometimes we do we're either too drunk to really care what we say to each other or, yah, so it's kinda hard. (Mark).

He also described how his sister had previously been diagnosed with TB and at first she had attributed her symptoms to her alcohol use and her liver backing up. Mark also noted that he initially thought his TB-related cough was due to his smoking and it was not until a friend intervened that he considered TB.

I just thought it was like either my smoker's cough or, you know, like just a mild cold ... I'd think of either an Advil or Aspirin and keep on going and,

¹⁷ On the survey, individuals were asked to state the length of time between the onset of their symptoms and their TB diagnosis (appendix I).

yah, I never suspected it would be T.B. or something, well serious yah.
(Mark).

In relation to community issues and substance use, only Rebecca noted that people in her community turn to drugs when things get tough and this behaviour affects their kids. Aiden also noted that a hardship for his community was that it was isolated and there were no roads, hospitals, or running water.

Other Diagnoses

Two of the individuals in the non-transmitter group commented on initially receiving diagnoses other than TB from their doctors. Nathaniel was initially told he had pneumonia and he saw the doctor three times before he was given an x-ray and received a TB diagnosis. Rebecca was also initially given a pneumonia diagnosis and given pneumonia medication and told to stay in the hospital. After a few days in the hospital, when she was getting ready to leave she was told she had TB and would have to stay in the hospital longer and take different medication.

I went to ex-rays and then doctor told me it was pneumonia then I was gonna be admitted for a few days 'til I get better or whatever. So I did and then that Friday I think it was Friday, no Thursday, she said "Things are looking good" and ... I was ready to go home ... And then that Friday doctor told me that I was diagnosed with TB and I was gonna be transferred over [to the Edmonton hospital]. (Rebecca describing her initial misdiagnosis).

Rebecca questioned why she was sent to the Edmonton hospital and not Calgary, since it was closer her home¹⁸.

Previous Knowledge of TB

All five in the non-transmitter group stated that they generally did not know a lot about TB. Mark did not hear anyone talk about TB before he got to the hospital and he previously thought that it was like pneumonia. Aiden also said that no one, doctors and nurses included,

¹⁸ Those residing outside the two central locations of Calgary and Edmonton are followed through by the AHS central TB services located in Edmonton (AHW, 2010). Rebecca was not from Calgary and was thus treated for her TB in Edmonton.

really talks about TB and he questioned why only ‘Indians’ got TB and why he never hears of White people being in the hospital for TB.

*How come it is only Indians they get it and no white guys doesn't get it? ...
`Cause I never heard to white guys are going into hospital for TB, nothing.
It could be they're not doing the right stuff in the hospital for them maybe.
(Aiden questioning why he never hears of White people being in the
hospital for TB)*

Aiden also knew a small amount of the history of TB within Aboriginal communities in terms of historically people having to stay in the hospital for many years for treatment. Nathaniel also had not heard of TB before he was in the hospital and Rosemary believed that TB was “no more” and she did not understand how one could get TB. Rebecca also said she had no previous knowledge of TB but she did comment on how she had seen TB related pamphlets at the health centre but that she did not think about them when she got sick.

Fear of TB and TB Transmission

Only the female non-transmitters talked about TB fear or stigma. Rosemary believes that people will act differently around her in her community and that she will have to isolate herself. Rebecca believes that people in her community are scared to talk about TB and that TB is just another thing that one can be stereotyped for.

I think most people are just embarrassed to admit that they had TB or they know somebody with TB and so they're, people know it's there, information is there and everything but it's just that nobody talks about it and that basically everybody's so shy or embarrassed to talk about it... Just people being stereo, stereotyped, mhm... Being made fun of and I guess it is like people over, people that are overweight get picked on and people that are skinny get picked on and they just, they don't add that list. (Rebecca describing why she thinks people in her community do not talk about TB).

Rebecca believes it is important for her family and friends to know that she had TB and she plans to tell them. The female non-transmitters are also the only ones that comment on a fear of transmitting the disease. They both worry about passing the disease on to their children. Rosemary gets very emotional during the interview when talking about this and the potential of transmitting the disease to her children. Because she does not want to transmit the disease to others, she has limited the number of visitors she has while in the hospital.

TB Transmission

Mark believes that transmission occurs because people do not go to the hospital when they are sick. Both he and his sister dislike the hospital and he says that there needs to be a more aggressive method to get people to take their medication, he suggests home care. Nathaniel is not sure why TB is transmitted but he believes he got it from a friend. Rebecca also believes she got TB from a friend who would not tell her specifically why he was in the hospital. She also believes that communities and people need a role model to talk about their experience with TB and share information with people. She believes that transmission is happening because people are not aware of the disease. Rosemary is married to a White man and does not live on the reserve she grew up on. When she visits her family on the reserve they tell her to go back to her “White world” and she believes that she would not have TB if she did not associate with people on Reserves. She wishes that health professionals could do something to help the people on reserves.

Health Care

For one of the non-transmitters this was not their first time with TB and three of the non-transmitters were aware of past contact with someone who had TB. All of the five non-transmitters indicated in the questionnaire that they believe there is adequate access to health care in their communities.

Recovery and the Future

Mark is interested in getting better and hopes that his experience with TB will help him re-evaluate his life and get it back on track. He hopes that it will motivate him to quit smoking. Nathaniel takes his medication because he wants to get better. Rosemary describes the hospital “like being in jail” and Rebecca cannot wait to go home because the hospital is “quiet and lonely”.

Culture and History

Only two in the non-transmitter group commented on culture and tradition. Aiden described how he likes to go into the bush to hunt or make tea. Rebecca noted that she was previously involved in travelling Pow Wows but in recent years had stopped as she was tired of travelling. She also smudges to help her get better and visits her grandmother, who she describes as a healer, to receive help with her prayer and smudging. Only two of the non-transmitters have regular family doctors and none of them have ever seen a traditional healer.

5.4 Narratives

Narratives were created to complement the visual representations and to summarize the information from the qualitative analysis into one story. Phenomenological research, as conducted in this thesis, is conducive to producing narratives to communicate the results of the analysis of an experience. Additionally, narratives are a successful way of “recording and communicating the essence of experiences and events of Indigenous societies” (Struthers, & Peden-McAlpine, 2005). Paul Draus, a public health fieldworker in New York city used a narrative approach in exploring patient’s experiences with TB. Draus felt that his narrative approach allowed him to “see his patients at a depth far beyond the limited ‘family history’ that is recorded in health care encounters” (Burke, 2011). Narratives allow the available information to go beyond the specifics of disease and treatment and include the dynamics of the patient’s life. Similar to the previous textual descriptions, the narratives utilize information from both the qualitative and quantitative data. The words in bold correspond to the words from the visual representations to facilitate connection between the text and figure.

5.4.1 Alberta Transmitter Narrative.

Jamie is an Aboriginal person from Alberta, Canada. Jamie has culture and smear-positive tuberculosis and has transmitted the disease to some family and friends.

Jamie is a **substance user**. Jamie drinks alcohol, smokes cigarettes and uses non-injection drugs. Alcohol is part of Jamie’s daily life and Jamie self-identifies as being alcohol dependent. Jamie is aware of the connection between alcohol use and health. Jamie talks about being “caught-up in the wrong crowd”, using drugs and having an unhealthy lifestyle. People in Jamie’s life said that in order to get better, the drinking must stop. Jamie saves up money to buy alcohol and believes that the “alcohol gotta save me”.

In relation to substance use, Jamie talks about **community issues**. Jamie has said that alcohol and drugs have led to violence and family breakdowns and that people do not care about their health – they drink a lot and they are sick but they do not care. Jamie believes that alcohol and drugs in the community are the reason that kids do not listen anymore and why they get into trouble.

Jamie has made the connection between **loss-of-culture** and **community issues**. Jamie believes that the loss of community land and the subsequent change and destruction have resulted in poor health and increased alcohol use in the community. Jamie reflects on the past and the memories of hunting in the bush with family. Jamie expresses disappointment and anger towards the loss of land, the changes that occurred, and the government. Jamie is angry that nothing could be done to prevent it. Jamie also comments on the violence against the environment and how life is all about money, power and drugs. Jamie reflects on the old days and how things were better when there were family values and before there was alcohol. Jamie believes that drugs and alcohol are taking over and the Elders say it is too late to do anything.

Jamie has faced **financial struggles**. Jamie felt that at the time of diagnosis it was too expensive to stay in the city to be near the doctor and receive treatment. Jamie has been “broke” and has had to rely on a son to pay the medical bills. When there is money, it is often spent on alcohol and gambling.

For Jamie, **substance use** was related to **patient-delay-in-seeking-treatment**. Jamie had five months between the onset of symptoms and receiving a tuberculosis diagnosis. Jamie initially attributed the TB symptoms to alcohol use and smoking. Jamie has engaged in excessive alcohol consumption and has said that at times there was “too much drinking to notice being sick” and Jamie “didn’t even notice the sickness was with me”. Jamie attributed the tuberculosis-related symptoms to drinking and smoking and believed they would go away over time. One of Jamie’s solutions to the symptoms was changing the drink of choice. Jamie also initially attributed the symptoms to drug use. Additionally, Jamie’s co-workers and family questioned whether the sickness was due to Jamie’s drug-use.

Jamie lived in an accommodation with more than one person per room and lived with multiple family members or household occupants. Jamie had forty-two close contacts. In the accommodation where Jamie lives, there are no pets or mould but there are smokers who smoke inside. The air ventilation is considered to be between fair and good.

Jamie noted a lack of **previous knowledge of TB**. However, Jamie had some awareness of the history of TB in Aboriginal communities and commented on how it seemed that TB affected Aboriginal people more than White people. Had Jamie known more information about TB, after the onset of symptoms, inquiry into the potential health problems would have occurred sooner. Jamie noted that there was a lack of **TB education** in the community. It is hard to get people in the community to talk about the disease. Jamie described that in the community no one cares and they do not talk about the disease with one another. Additionally, Jamie talked about **fear of TB** in the community. A family member of Jamie's was fearful after the initial diagnosis of TB. Jamie believes that children may be teased at school if they talk about TB and believes that when people think about TB they think of the historical and negative aspects about it, ex. Sanatoriums.

Jamie had **another diagnosis before receiving a TB diagnosis**. Jamie also described having a negative relationship with the doctors sometimes. Jamie felt that the doctors were perhaps not responding seriously to the symptoms and illness and that the doctor was just prescribing any type of medication to Jamie, not considering the symptoms, because the doctor believed Jamie just wanted medication. Jamie did note that once it was discovered that the sickness was TB, admission to the hospital occurred immediately.

In general, Jamie wants to **get better and recover from TB**. Before the diagnosis, Jamie wanted to know what was wrong and hopes that the sickness will be cured. Jamie does not want to die and hopes that the sickness will be motivator to be active again and move on from the negative situations of the past. Jamie believes the best thing is to stay in the hospital and listen to the doctors until recovery.

Jamie has some **fear of transmitting** the disease to children. Jamie believes it should be a priority for children to be checked, but that people will not focus time or resources on having their children checked for TB because they do not care. Jamie again notes that TB continues to be transmitted in the community because people do not care about their health – they are drinking a lot and they are sick but they do not care.

5.4.2 Alberta Non-Transmitter Narrative.

Alex is an Aboriginal person from Alberta, Canada. Alex has smear- and culture-positive pulmonary tuberculosis but has not had significant transmission of the disease to contacts.

Alex drinks **alcohol** but is not considered to be alcohol dependent. Alex is also a **smoker**. Alex notes that a typical day may include going to the liquor store and that sometimes arguments with the family occur and they are too drunk to care what they say to one another. Alex has a sister who was previously diagnosed with TB and at first she had attributed her symptoms to her alcohol use and thought it was her liver backing up. Alex initially thought that the coughing related to the TB was due to smoking, and it was not until a friend intervened that Alex considered the symptoms to be indicative of something more. Alex commented on the hardships in the community and how people in the community often turn to drugs when things get tough and this behaviour affects their kids.

Alex had a **delay-in-seeking-treatment** of ten weeks. In response to sickness, Alex prefers to “cough-it-out” and just let things recover on-their-own. When sick, Alex likes to take care of oneself and “stick-it-out” until recovery. Alex has twelve close **contacts**. Alex enjoys being alone and having **independence**. Alex has very few friends, does not keep in contact with family and feels that there is not a lot of **support** in life. Alex lives in an accommodation with less than one person per room. There are pets in the house but there is no mould. There are smokers who smoke inside and the air ventilation is considered to range between good and very good.

Alex initially received **another diagnosis** of pneumonia from the doctor. Alex was given medication that did not resolve the sickness before receiving an x-ray and a TB diagnosis.

Alex had no **previous knowledge of TB**. Alex said that no one really talks about TB but questions why only ‘Indians’ get TB. Alex was aware of some of the history of TB within Aboriginal communities but believed that TB was “no more”. Alex believes that TB transmission continues to occur because people do not go to the hospital when they are sick. Alex believes that there needs to be a more aggressive method to get people to take their medication and suggests home care. Alex also believes that communities need a role model to step-up and talk about their experience with TB. Alex believes that TB transmission continues because people are not aware of the disease and wishes that health professionals could do something to help the reserves.

Alex is interested in **getting better** and hopes that the experience with TB will result in a re-evaluation of life. Alex will take the medicine and comply with the doctors in order to get better.

Alex did not comment much on culture but briefly described how it is enjoyable to go into the bush to hunt or make tea. Alex also prays and participates in smudges to help get better.

5.4.3 Male and Female Differences in the Non-Transmitter Group.

There seemed to be some gendered differences in the TB experience of the non-transmitter group. In the non-transmitter visual representation, characteristics unique to the female non-transmitters are seen in purple and characteristics unique to the males are seen in green. There were two female non-transmitters and three male non-transmitters. The males described themselves as independent and as not having a lot of support. The female non-transmitters however commented on the importance of their family and family support and that their life revolves around their family, especially their kids.

Only the female non-transmitters talked about fear related to TB. One female believes that people will act differently around her in her community and that she will have to isolate herself. The other female believes that people in her community are scared to talk about TB and that TB is just another thing that one can be stereotyped for.

The female non-transmitters fear transmitting the disease. They both worry about passing the disease on to their children. Rosemary gets very emotional during the interview when talking about this and the potential of transmitting the disease to her children. Because she does not want to transmit the disease to others, she has limited the number of visitors she has while in the hospital and as a result experiences loneliness during her stay.

The female non-transmitters also comment on the negative aspects of being in the hospital. One non-transmitter describes the hospital “like being in jail” and the other female non-transmitter cannot wait to go home from the hospital because it is “quiet and lonely”. It is the first time she is away from her children for this long and misses them. She worries about getting the Christmas shopping done and about being away from her two young children for so long.

5.5 Comparison of Alberta Transmitter and Non-Transmitter Groups

As this was a comparative project looking to identify unique factors associated with TB transmission, a discrete comparison piece is required that highlights the factors that emerged as being distinct between the two groups and potentially relevant to transmission. The visual representation of the emergent themes and demographic charts suggest there are three main areas

that are different between the TB experience of those who transmit and those who do not: (1) patient delay in seeking treatment, (2) substance use and (3) number of contacts.

Substance Use

Of the transmitters, five consumed alcohol and three were identified, based on responding yes to a number of questions in the survey, as being alcohol dependent. Of the five who consumed alcohol, three consumed greater than ten drinks per week. Three non-transmitters consumed alcohol but only one was identified by the survey responses as being alcohol dependent. Three transmitters were smokers and two non-transmitters were smokers. Four transmitters were non-injection drug users with the one remaining transmitter being a former non-injection drug user. Only two non-transmitters were non-injection drug users and the three that were not current users had never used non-injection drugs. The qualitative interviews also revealed a greater impact of substance use in the transmitter's lives. Four of the five transmitters noted the influence of alcohol in their daily lives, in their communities and reasons for their decreased health. Many of the transmitters initially attributed their TB symptoms to their alcohol and tobacco use. Though the non-transmitters made some comments towards substance use in the qualitative interviews, their descriptions of the impact it had in their lives was less. Only one non-transmitter had initially attributed his TB symptoms to smoking.

Patient Delay in Seeking Treatment

The qualitative interviews revealed a relationship between substance use and patient delay in seeking treatment in the transmitters. The transmitters had a average TB diagnosis delay of five months (ranging between four and thirty-six weeks) and many transmitters noted in their interview that they delayed seeking health treatment because they believed their symptoms were due to their alcohol use or cigarette smoking, "there was too much drinking to notice being sick". One transmitter had decreased access to health services because he had been "kicked-out" of his town due to his excessive alcohol use. The non-transmitters had a shorter average TB diagnosis delay of two-and-a-half months (ranging between four and sixteen weeks). The qualitative interviews reveal that accessing health services was less influenced by substance use in the non-transmitter group than in the transmitter group. Additionally, in the non-transmitter group there was increased fear of transmitting the disease and the female individuals of the group talked heavily about the importance of family and support. These considerations may have motivated the non-transmitters to seek health care sooner. Patient delay in seeking treatment may increase

transmission events as the infected individual is not receiving appropriate treatment for an increased time. Additionally, increased patient-delayed diagnosis may increase the number of contacts an infected individual has. This in turn may increase the number of people who are exposed to and become infected by the disease.

Contacts

The transmitters had an average of forty-two close contacts (ranging between eight and seventy-seven) compared to an average of twelve close contacts of the non-transmitters (ranging between two and twenty-two). Two non-transmitters made specific reference to their independence and enjoyment of being alone. There is a potential connection between increased patient delay in seeking treatment and number of contacts as increased time not seeking health care increases the infectious period and the number of people that one is in contact with in daily life. Related to number of contacts is housing density. The questionnaire asked participants information on the number of individuals living in the same accommodation and the number of rooms in the house and thus housing density could be calculated. Although, there is unknown information, the known housing densities of the transmitters were 2.25, 0.67 and 2.4. One transmitter was homeless and one lived in shared accommodations and thus housing density could not be calculated. Interestingly, the transmitter with the lowest housing density, 0.67, also had the lowest number of points when the transmitters were ranked (seven points). The non-transmitters had housing densities of 0.6, 1, 0.67 and 2.14. The fifth non-transmitter lived in a shared accommodation and therefore housing density could not be calculated. The non-transmitter with the greatest housing density was also the individual with the highest number of transmission points, three, within the non-transmitter group. Increased housing density may result in increased contacts and potentially increased transmission events.

5.6 New Zealand

An additional component of this project was a cross-cultural comparison examining the experience of having TB in the Maori and Pacific people of New Zealand. The following section includes demographic information of the participants whose interviews I accessed and analyzed, a visual representation of the factors relevant to the TB experience, a textual description of the experience, a summary narrative, and a comparison of the New Zealand TB experience to the Canadian experience.

5.6.1 Demographic Information of New Zealand Participants.

The following tables (table 5.4 and table 5.5) outline the demographic information of the Maori and Pacific participants whose interviews were accessed.

Table 5.4: Demographic and patient characteristic information of the five Maori pulmonary TB patient interviews conducted by Moana Oh. The interviews were used in secondary data analysis to evaluate the Maori experience of TB and compare factors relevant to TB transmission with Canadian data (adapted from Oh, 2005).

Patient	Age	Gender
Kowhai	24	Female
Pita	45	Male
Rangi	37	Male
Reka	54	Female
Ngaire	72	Female

Table 5.5: Characteristics of interview participants of Pacific TB interviews conducted by Roannie Ng Shiu. These interviews were used in secondary data analysis to evaluate Pacific people's experience of TB and compare factors relevant to TB transmission with Canadian data (adapted from Ng Shiu, 2006).

Participant	Ethnicity	Age	Gender	TB status
Sarah	Tuvaluan	N/A	Female	Family member with pulmonary TB
Makelita	Samoan	N/A	Female	Husband with pulmonary TB
Mateo	Tuvaluan	50	Male	Pulmonary TB
Mere	Cook Islander	79	Female	Pulmonary TB
Sina	Samoan	64	Female	Pulmonary TB

5.7 Visual Representation of New Zealand TB Experience

Similar to the Canadian data, a visual representation was created based on the factors that emerged as being relevant to TB in the Maori and Pacific interviews (figure 5.3, p.90). Again, because of the different nature of the two countries' projects, the information obtained is

different. As previously mentioned, it was not possible to differentiate the New Zealand participants into transmitter and non-transmitter groups as had been done in Canada. The New Zealand visual representation therefore describes the relationship between the factors that emerged as being relevant to the whole TB experience. The dashed line indicates that these factors may be relevant to TB transmission, which will be discussed further. In the visual representation, the red line underneath some words connects the factors identified in the Canadian data and consistent with the New Zealand data. The green texts indicates the factors that were relevant to both Maori and Pacific patients while the pink text highlights factors more relevant to the Maori and the orange text the factors more relevant to the Pacific patients. The ‘plus’ and ‘minus’ symbols indicate the positive or negative nature of the factor. In some cases, the factor was positive for some participants but a negative thing for others.

Additional sources of data in the New Zealand study include information from Dr. Debbie Hay, an Auckland communicable disease physician who completed her dissertation in tuberculosis treatment, and from reviewing journal articles that reported on TB outbreaks in Maori and Pacific communities in New Zealand.

5.8 Textual Description of New Zealand Information

Although the above-mentioned documents were not developed with the sole intention of describing factors associated with tuberculosis transmission, the information obtained from them highlights issues, potentially relating to TB transmission, that are relevant within the Maori and Pacific populations of New Zealand.

Substance Use

Both Oh and Hay noted that they believed alcohol was an issue for some of their cases even if it was not made explicit throughout the interviews. Hay also described how for some patients the initiation of a cough was attributed to smoking. Although most Maori and Pacific patients were not asked about their substance use some mentioned it in their interviews. Kowhai, a Maori woman with pulmonary TB, noted that prior to her TB diagnosis she was drinking a lot.

[I was] just drinking, drinking lots. Um, lots of alcohol, almost everyday I was drinking, for about three or four months. (Kowhai describing her life in Auckland prior to her TB diagnosis).

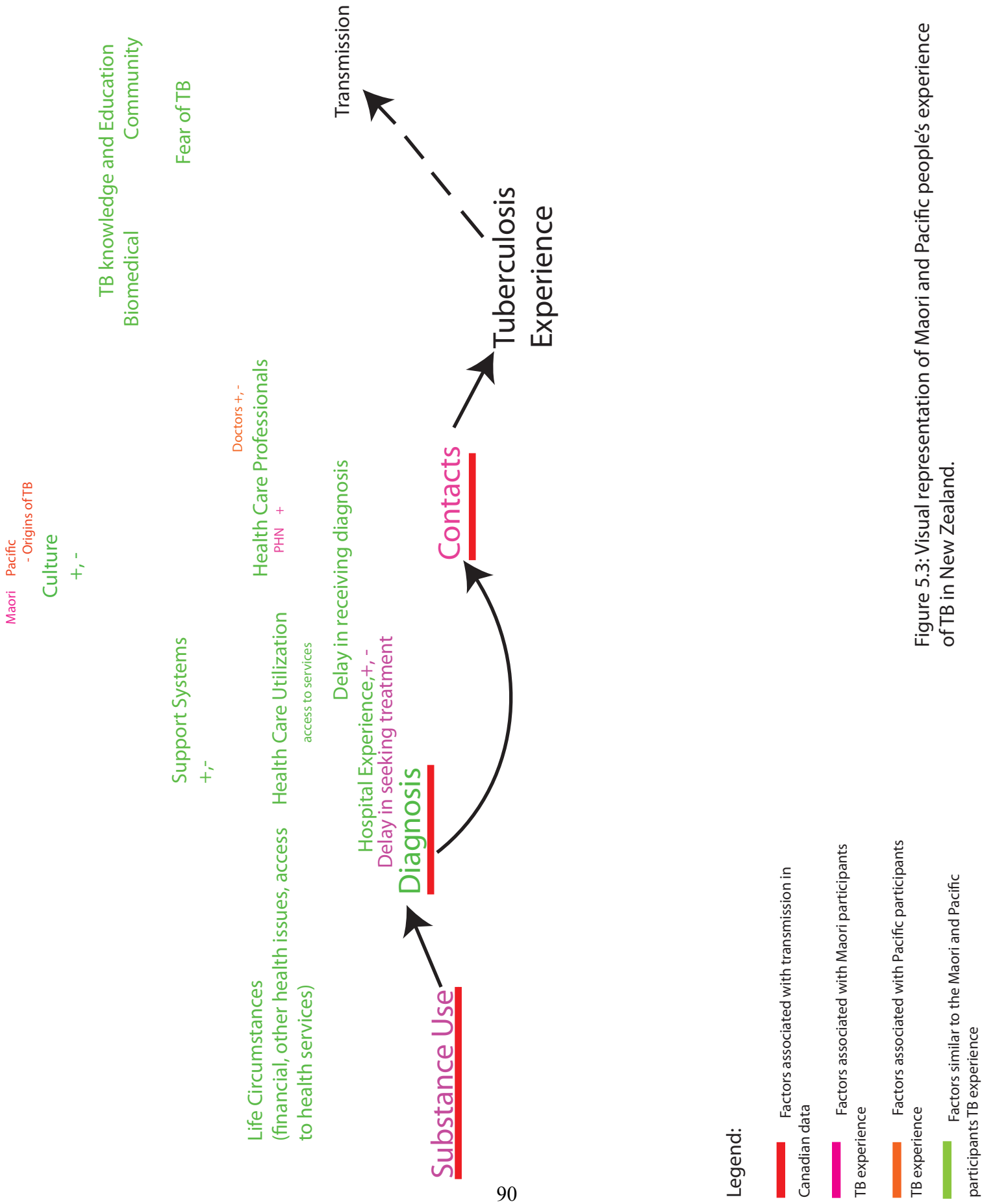


Figure 5.3: Visual representation of Maori and Pacific people's experience of TB in New Zealand.

Additionally, in relation to substance use and TB symptoms, Pita, a Maori man, initially thought his symptoms were due to his smoking and his family questioned whether they were due to his methamphetamine use.

Contacts

Although none of the patients provided much detail on their contacts or social activities prior to their diagnosis there were some specific references to contact situations that could facilitate increased transmission. Prior to TB diagnosis, while in the hospital being tested, Pita noted that he was permitted to wander the hall of the hospital and thus have regular contact with patients, nurses and other hospital staff. Once he was diagnosed, all the individuals on his floor in which he could have been in contact with had to be tested for TB. Rangi often “hitched a ride to work” as he believed it was a good way to meet people. Ngaire liked to be social and go all over the place to visit with friends.

Social Factors

Other social issues including financial struggles, family violence and crime are relevant to transmission. Hay noted that individuals with financial issues may have difficulties in, among other things, getting to appointments. For one Pacific woman, because of the cost of transportation, her husband would have been unable to get to follow-up treatments had they not had financial help.

I used to come by taxi everyday to see him so they finally said they gonna give us vouchers for taxi to take us there and come back and I was really happy about that...It cost between 34 to 36 dollars a day. It's like 18 to 20 there depending on traffic so it's a lot of money so I was thankful when they issue those vouchers and we go there every morning. (Makelita)

Family violence and crime were discussed. They can result in increased mobility and make it difficult locating people, increasing the complexities in contact tracing and getting treatment for people that may be infected. Oh noted that she felt that for many of the Maori participants, due to social complexities, patients were unable to make a health a priority in the same way someone would who did not face these challenges daily.

Access to Health Services

Rural living increases the distance that patients must travel to seek medical treatment or get to follow-up appointments in larger centres. Kowhai, once discharged from the hospital, missed two of her appointments as she and her partner were living in a rural location, were not driving at the time, and could not arrange for a ride to the appointment. Additionally, the family members of one TB patient did not want to travel the long distance in order to be tested.

Physician

Hay mentioned that some of her patients expressed wishes of having doctors who spoke their language and understood their culture and their unique cultural needs. Two Pacific interviewees also noted the importance of having a doctor who was from their same island country and could speak their language. For Mateo, there was not a general physician on the island he was living on in Tuvalu, and his first experience with a GP was in New Zealand. He did not like his first GP and when he found out about a Tuvaluan doctor he changed doctors. He noted that he likes that his doctor is from Tuvalu and that he speaks Tuvaluan and understands him. Additionally, Mere liked that her doctor was also from the Cook Islands. Interestingly, the Public Health Nurses (PHN) are often not of the same ethnicity as the patient yet many noted positive relationships with their Public Health Nurse. This may be indicative of the importance of developing and nurturing the health professional – patient relationship that often occurs with the PHNs.

Hospital Experience

In two cases with the Maori patients, negative experiences with the doctors resulted in them attempting to leave the hospital before being discharged. Pita, who while in the hospital attempted to escape but was caught and returned to the hospital immediately. However, in the second case, Kowhai was able to return to her family and her home. This increased the number of people Kowhai was in contact with and that she could have transmitted the disease to. She felt compelled to leave the hospital because she felt the doctors were not explaining what was happening to her.

But while on treatment, um, I don't know, I just couldn't take it anymore, and I took off, I went home. Didn't say nothing to the doctors just went... because they weren't telling me what to do, what I needed or you know,

what kinda, they weren't even breaking their big words down for me. As much as I asked them, "arr look, can you explain that better? I can't understand your medical terms". They couldn't do that. So I rang for an [advocate] ... And apparently the advocate for that area was on holiday when I did it...[and] they didn't supply me with one. (Kowhai).

Hay described another situation in which an individual went to the hospital seeking medical attention. He felt overlooked while waiting for tests at the hospital and thus left, increasing the time that he was not diagnosed, not on treatment, and potentially able to transmit the disease to his contacts.

Fear of TB

Fear of TB was mentioned in the Pacific interviews. In the Pacific context, most people, though they initially feared TB, felt that it was okay because there was effective treatment for the disease.

Oh yah, because like it's scary, but it's okay now you know because it's curing. (Sarah).

Additionally, some Maori patients noted how they felt they were being ostracized due to their TB. Rangi was asked to leave his home following his diagnosis and felt that his friends decreased contact with him. Ngaire felt that when she went back to work, even though she was no longer infectious and had been cleared to work, people feared her and kept their distance.

I finally got clearance and off I went back to work. But, in, in, that happening there was this sense that I felt, that people were staying clear of me. (Ngaire).

Delay in Receiving TB Diagnosis

Hay, an experienced TB physician, stated that in her opinion, delayed diagnosis, both patient and health-care delay was the leading reason for TB transmission. Given the high infectivity of the disease and that there is efficient treatment, early diagnosis and initiation of treatment is crucial in preventing disease transmission and ultimately, the incidence of the disease. In this analysis, both patient and health-care delay were prevalent. In one case, Kowhai

did not want to seek health care upon becoming sick and only did after involvement from her partner. Health care delay occurred when a doctor did not consider TB as a diagnosis initially for one individual and in another case, Pita was given a diagnosis of psychosis without the doctors inquiring about his previous health symptoms. For one Pacific patient with pulmonary TB, Mateo, he delayed seeking medical attention and as a result four children in his household became infected, with two resulting in tuberculosis disease (Ng Shiu, 2006).

Support

The partner of Kowhai noted that family support was important to provide for patients and this was something that most interviewees mentioned, whether they had support or their thoughts on the fact that they did not. Kowhai's partner was there for her throughout her experience.

My honey, she was there, for me, right through out it. I mean, she even slept, well, if we could get away with it, she even slept in my bed at the hospital. Otherwise we were on the floor, sleeping on the floor. (Kowhai).

Kowhai's partner, as a supporter, noted that support is the most important factor for TB patients during their treatment.

I was willing to go back to hospital with her and stick it out with her, you know, till however long it took. (Kowhai's partner).

For many their family support was a positive aspect of their experience and something that helped them stay strong throughout the situation. For others, a lack-of-support was difficult and something they wished for. For one patient, familial support was not a positive issue. Pita had many issues with his family including disputes over land-ownership and a situation of aggressiveness towards his sister which resulted in him being arrested and going to jail. He felt that his other brothers and sisters sided with the one sister and that, combined with their fear of TB, was why they did not visit him in the hospital. He wanted his family's support, but only one of his thirteen brothers ever visited. He did find some support with a hospital group.

Also, in relation to support, the public health nurse was mentioned by Hay and in Oh's interviews. It was seen as an important relationship and many of the Maori participants had

positive experiences with their PHN. The relationship with the public health nurse is important. As noted above, the PHN is the person who provides information to the patient and administers treatment. For Kowhai, who had a difficult time initially in the hospital, the public health nurse told her she had to return to the hospital for her treatment. The PHN developed a treatment contract for her to follow and helped her avoid the legal issues of not following treatment. Kowhai noted that things were much easier because of the PHN. Additionally, both Pita and Rangi describe the PHN as being great.

Judy [Public Health Nurse] is the best, she's the best, I must say, she's the best. If I, if it wasn't for Judy I would have been locked down. But she had so much patience with me. She did, she had a lot of patience, I was just a real bitch. I was that stubborn, that she would wait and wait and wait for me to calm down. Or, she, oh god, I just love her really, I must say. To take me on, shucks. (Kowhai).

Culture

In the Maori interviews, for some, being Maori was a source of pride and for others was seen as shameful. Reka noted that it was the strength from being Maori that allowed her to persevere through her TB and treatment.

[Being Maori] means everything, to me ...well being Maori means um, to be proud of who you are, no matter where you come from me, is to be proud. And I am very proud. (Reka).

Kowhai was ashamed of being Maori. She did not think that it had an impact on her treatment experience. She believed that Maori people should not be given special treatment and should access services in the same way that everyone else does. Another Maori individual did not want to be labelled as Maori and wanted to be considered just as a New Zealander.

Although the Pacific interviewees did not speak strongly about the role of culture, some views on cultural identity emerged through the views on traditional medicine and beliefs about sickness being a result of living in New Zealand. Some believed that TB was something that would not have occurred had the patient stayed in their home country. Three of the cases

described how they did not believe they (or their family members) would have gotten TB if they were still living in the islands. Sarah did not believe that there is any TB back in Tuvalu¹⁹ and she said her son would have only got TB because of living in New Zealand. Mateo, also from Tuvalu, said “I believe that this one wasn’t from the island”. Makelita believed that if she and her husband were living on Samoa he would not get sick and noted how she said to him “I’m getting sick of you since we’ve been coming to NZ, you always sick and always in hospital”.

5.9 New Zealand Narrative

Jesse is a Maori person from New Zealand who has been diagnosed with pulmonary tuberculosis. Jesse is a **substance user** and some family members initially questioned whether the TB symptoms were due to smoking. Jesse made the connection between substance use and poor health in that due to excessive alcohol consumption the TB was “waking” within. Jesse experienced patient **delay in seeking treatment** and initially attributed the TB symptoms to the flu and did not want to seek treatment but “deal with things on my own”.

Jesse felt that people changed their attitudes upon discovering that Jesse had TB. Jesse felt that people outside the *whanau* (extended family) acted differently and gave Jesse different looks as they feared TB transmission. Once discharged from the hospital, Jesse was “asked-to-leave” the boarding-house by the landlady due to the TB diagnosis and Jesse explained that contact was lost with many friends.

Jesse initially had a negative relationship with the **doctor** and a negative **hospital experience**. Jesse believed that the doctors saw Jesse “as a diagnosis, rather than a person” and would not take the time and explain what was going on. Jesse “just couldn’t take it anymore” and felt overwhelmed by the doctors “who weren’t telling me what to do... weren’t even breaking their big words down for me”. This resulted in Jesse leaving the hospital before being released and returning home and having contact with family. Jesse did return to the hospital after convincing by a partner and the **public health nurse (PHN)**. The relationship with the public health nurse was important for Jesse and Jesse described the PHN as being great and very supportive.

¹⁹ Despite Sarah believing there was no TB in Tuvalu, Tuvalu has the highest rate of TB throughout the Pacific islands (World Health Organization, 2010).

Jesse has had a relatively positive experience with **family support**. Family encouraged Jesse to stay in the hospital until complete recovery. However, family was not all positive as Jesse had some disputes with family over land-issues. Jesse sometimes wished there was more family support and visitation in the hospital. Jesse also found support with a hospital group.

Jesse noted very little **TB knowledge** prior to diagnosis. Jesse was aware of some aspects of the disease and transmission however and said the hospital staff had explained some aspects of the disease during the time in the hospital. Jesse did show some evidence of understanding stress and the immune system in relation to TB.

Jesse did not provide a lot of information on social activities participated in prior to TB diagnosis or **contacts**. Jesse did describe that prior to the TB diagnosis, permission was granted to wander the halls and have regular contact with patients, nurses and other hospital staff. Prior to being in the hospital, Jesse often “hitched a ride to work” as it was a good way to meet people.

Rural living was an issue for Jesse. Once discharged from the hospital, Jesse missed two appointments due to living in a rural location, not driving at the time, and not being able to arrange for a ride to the appointment.

Jesse did not believe that being **Maori** affected the hospital or treatment experience. Jesse was “just another patient really, with the same problems as everyone else that had it”. Jesse believes that “not much has been done in the way of Maori health” and that although the *Treaty of Whaitangi* is meant to stand for equality, “it stands for Maori being ripped off, it has done nothing”. Jesse believes that Maori are treated like second class citizens, questions “why the Pakeha are governing our land” and states that “we should be walking together”.

Pacific Island

Amari is a Pacific person living in New Zealand and was diagnosed with pulmonary tuberculosis. In comparison to Jesse, Amari has experienced several commonalities with TB treatment in New Zealand. However, there are some experiences that are unique to being a Pacific person as compared to being a Maori person. Amari was initially shocked after receiving a TB diagnosis, but once told that it was curable, the **fear of TB** decreased and there was less concern. Before the doctors confirmed a TB diagnosis, the doctors told Amari they hoped it was TB and not cancer, because TB has a cure. Amari’s family was initially worried but it became okay, “oh yeah [they were worried] ... because like it’s scary... but it’s okay now you know because it’s curing”.

In relation to the **origins of TB** Amari believes that “this one wasn’t from the island, from here” and that TB is only relevant in Amari’s life due to living in New Zealand, it would not have occurred if living on the island. The relationship with the **doctor** was important for Amari. It was important that Amari’s physician be from the same Pacific island as Amari was. **Financial issues** were relevant for Amari in relation to **health care utilization**. Upon returning home from the hospital, Amari was not able to get to follow-up appointments without taxi vouchers.

5.10 Comparison of New Zealand and Canadian TB

The factors that emerged as being distinct between the transmitters and non-transmitters from the Canadian data were sought in the New Zealand interviews. The following section describes the comparison of the three distinct factors from the Canadian transmitters: high substance use, patient delay in seeking treatment and number of contacts within the New Zealand experience of TB.

Substance Use

As previously noted substance use emerged in the Canadian data as being greater in the transmitters and strongly influencing treatment-seeking actions as well as other life conditions. Although alcohol and smoking were mentioned in some of the Maori interviews, the extent that it was described as resulting in delayed diagnosis in the Canadian data, was not the same in New Zealand. Kowhai, a Maori woman, noted that prior to her TB diagnosis, she moved to Auckland and drank heavily for three to four months and was smoking every day. Upon initial development of TB symptoms, Pita’s family questioned whether his symptoms were due to his methamphetamine use. Although issues of alcohol, tobacco and other substance use were not as evident in the New Zealand interviews, both Oh and Hay believed that for some of their participants, alcohol and drug abuse were an issue and potentially related to their TB and health care experience.

Patient-Delay-in-Seeking-Treatment

Secondly, patient delay in awareness of symptoms and in seeking treatment was an important issue in Canada between the transmitters and non-transmitter groups. Transmitters had a delay of approximately five months between initial onset of symptoms and receiving a TB diagnosis, while non-transmitters had a delay of approximately one-and-a-half months. The

extent of the patient delay in seeking treatment was not captured explicitly in the New Zealand data as it was in the Canadian data, however, some patients did speak about delays during their interviews. In two cases with Maori participants, the infected individuals did not want to seek treatment upon development of their symptoms and only did so after encouragement from their partner. One individual believed their sickness was just the flu and that it would go away in time. Other reasons for delay in seeking treatment was the belief that the sickness would go away in time and fear of hospitals. Hay believes that delayed diagnosis, both patient-delay and health-system delay, is the number one reason that TB transmission occurs. Similar to the Canadian experience of TB for both the transmitters and non-transmitters groups, delayed diagnosis due to health care problems occurred in New Zealand. In Canada, many patients experienced initial misdiagnoses of pneumonia or bronchitis and subsequently received inappropriate treatment. While misdiagnosis also occurred in New Zealand, patients also spoke of not receiving a diagnosis or not completing treatment due to negative experiences with the health care system. One New Zealand patient sought out treatment and a diagnosis in the hospital. However, he felt he was not being treated properly and in a timely manner and decided to leave the hospital without a diagnosis. As a result, he spent an additional two to three months without a TB diagnosis, was not receiving treatment, was in contact with other people and potentially infecting them. A Maori patient, Kowhai, experienced negative feelings towards her doctors after TB diagnosis, while in the hospital. She felt that the doctors were not explaining her disease and treatment to her. She was fed up, left the hospital and returned home where she was in contact with a number of family members. For one Pacific patient, delay in seeking treatment occurred. Mateo delayed seeking treatment upon initiation of TB-like symptoms and subsequently children in his household also became sick with TB.

Contacts

Finally, increased number of contacts between the transmitter and non-transmitter groups was identified in the Canadian data. Transmitters had an average of forty-two close contacts, while non-transmitters had an average of twelve. Again, explicit information as to the number of contacts each Maori and Pacific patient had is not known. Information did emerge as to social habits in the interviews however. The delay in diagnosis that some New Zealand patients may have experienced will contribute to an increase in the number of contacts a patient has. Noted activities of some Maori and Pacific TB patients, including hitch-hiking, enjoying

being social and being allowed to wander the halls in the hospital prior to TB diagnosis, all indicate that TB transmission could occur between TB patients and the individuals they are in contact with while infectious.

One theme that resonated between the two contexts was the notion of “priority of health”. In New Zealand, both Oh and Hay noted that they believed that for their patients and interview participants, personal health may not always be a priority. These are people who face complex social situations every day and as a result of having to always deal with other issues, health may not always be a priority. This is similar to the Canadian context. From both the interviews as well as personal communication with TB doctors and researchers, these patients are individuals from marginalized populations who face complex social realities such as co-morbidities, including substance abuse and addictions, criminal and gang activity, poverty and other financial struggles, and complex family and social networks and relationships etc. As a result, health, and seeking health treatment is not always a priority in the way that it is for someone who does not face these challenges.

5.11 Summary

The previous section outlines the results of the data analysis in both Canada and New Zealand. In Canada, using molecular and epidemiological techniques, I was able to differentiate my ten Alberta Aboriginal TB cases into transmitters and non-transmitters and compare their TB experience through interpretive phenomenological analysis of the qualitative interviews. Substance use, patient delay in seeking treatment and number of contacts emerged as being increased or greater in the transmitter group than the non-transmitter group. Though not as explicit, these social factors are all relevant in the Maori and Pacific people’s experience of TB and may highlight social factors, existent in the New Zealand context, relevant to TB transmission. The following chapter further discusses these three factors and their relevance to TB transmission. The discussion explores other literature on these factors and the programs and research that exist that address these and other transmission related factors.

Chapter Six: Discussion

Chapters two and three of this thesis outlines the background literature surrounding tuberculosis transmission within Indigenous people in Canada and New Zealand. Chapter four discusses the methods and includes information regarding the data collection and analysis that occurred for the project and chapter five highlights the results of the study. In Canada, when comparing the transmitter and non-transmitter groups, three factors emerged as being of importance for understanding transmission: substance use, patient-delay-in-seeking-treatment, and number of contacts. All five in the transmitter group consumed alcohol at the time of diagnosis and three were identified as being alcohol dependent based on their responses to a series of questions in the survey. Three of the five in the non-transmitter group consumed alcohol and one was identified as being alcohol dependent based on the survey. In the interviews, transmitters spoke more about the habitualness of alcohol consumption in their lives. The second factor identified was delayed diagnosis. The transmitter group had an average of five months of delay from the initial onset of symptoms to the time of a tuberculosis diagnosis while the average delay in the non-transmitter group was one-and-a-half months. In this project, a connection between substance use and patient-delay-in-seeking-treatment emerged as a significant issue in the transmitter group. In their interviews, transmitters commented much more on how they may not have been aware of their symptoms due to their substance use or believed their symptoms to be due to their substance use. Additionally, the transmitter group had an average of forty-two close contacts while the non-transmitters had twelve. Comparing this information within the New Zealand Maori and Pacific people's experience of TB reveals that social factors relevant in the Canadian context of transmission are relevant in the New Zealand Indigenous experience with TB.

This chapter identifies the comparable social factors between the transmitter and non-transmitter groups and explores how these factors may be associated with increased tuberculosis transmission risk, including their association with other social determinants of health and increased risk of tuberculosis transmission. This chapter also includes a discussion on the Indigenous frameworks of health that were discussed in chapter three and utilized within this study as a means of placing the social factors associated with increased tuberculosis transmission within the frameworks and exploring these factors with other components of health. Finally, this chapter discusses the strengths and limitations of the research project.

6.1 Substance Use

Alcohol use is said to be one of the most relevant proximal determinants of health for Aboriginal people (Reading & Wien, 2009). Alcohol was first introduced to the Canadian Aboriginal people by European traders in the 16th Century with the fur trade (McCormick, 2000; Waldram, Herring & Young, 2006). Prior to this time, Aboriginal people had no experience with alcohol, but with the introduction of the fur trade, alcohol became a popular gift and trading item (Waldram, Herring & Young, 2006). In contemporary society alcohol has been said to be used as a method of escape to numb the pain of abuse and “cultural dislocation” as a result of colonization (McCormick, 2000). In North America, the rate of drug abuse is much higher in Aboriginal people than non-Aboriginal people and almost three-quarters of all deaths caused by accidents and violence among Aboriginal people have been linked with alcohol and substance use (McCormick, 2000). For many Aboriginal people, alcohol consumption has been a way to deal with the perceived state of powerlessness and despair that has arisen due to the breakdown and devastation of traditional cultural values. Research studies have observed a link between alcohol abuse and cultural breakdown (McCormick, 2000) and some researchers believe that “substance abuse is a survival mechanism for Aboriginal people whose culture and values have suffered due to assimilation” (Pedrigo, 1983 in McCormick, 2000). In a study that asked Aboriginal people what they believed the greatest social problem within their community to be, 61.1% reported that alcohol abuse was the greatest social health problem (Adelson, 2005).

In this study, many of the transmitters indicated that they believed their TB symptoms were due to their drinking or smoking and that they would go away in time. Many transmitters stated that there was “too much drinking” to notice being sick. Others initially attributed their symptoms to a cold or the flu and again believed it was not serious and would go away in time. A systematic review of the notion of alcohol as a risk factor of tuberculosis (Lonnroth et al., 2008) found that the pooled relative risk of alcohol use and tuberculosis was 2.94 (CI: 1.89 – 4.59) and the authors concluded that the risk of active tuberculosis is elevated in people who drink more than 40g of alcohol per day or are considered to have an alcohol use disorder. They noted that this increased risk may be due to increased risk of infection related to specific social activities, which can be linked back to the number of close contacts, a potential relationship also identified in this project, as well as the effect of excessive alcohol consumption on the immune system and an individual’s overall health (Lonnroth et al., 2008). In relation to transmission, a

2009 systematic review found a significant positive association between alcohol abuse and TB clustering and reported that recent transmission of TB was associated with heavy alcohol use. The authors noted that there is evidence from several research studies, from both high and low incidence TB countries, that there is a clear and strong association between heavy alcohol use, the risk of developing active TB and the risk of recent TB transmission (Rehm et al., 2009). Studies have noted that recent transmission prevails in people with high-risk behaviours (including alcohol abuse) in that these behaviours are often associated with increased exposure to new infections and decreased personal care habits (Nava-Aguilera et al., 2009).

Although substance use was not as frequently described by Maori or Pacific individuals nor was an explicit connection made between substance use and diagnosis delay as in the Canadian component, both Hay and Oh noted they believed alcohol use was a factor of some of their study participants lives. One Maori woman, Kowhai, noted how her social activities prior to her hospitalization and tuberculosis diagnosis included heavy alcohol consumption and Pita, a Maori man, initially thought his symptoms were due to his smoking and his family questioned whether they were due to his methamphetamine use.

Like Canadian Aboriginal people's experiences with colonization, loss of land, urbanization, breakdown in traditional tribal structures and the loss of dignity, respect and identity due to European colonization and the results of the Treaty of Waitangi, have resulted in health disparities between Maori and non-Maori, including rates of alcohol and drug use (Sellman et al., 1997). Alcohol morbidity and mortality for Maori people is experienced at a greater rate than for non-Maori people and Maori people present at health care services for a variety of alcohol-related problems at a greater frequency than non-Maori (Mancall, Robertson & Huriwai, 2000). For Maori people, colonization and long-term effects including increased rates of unemployment, low paid employment, poverty and experiences of racial discrimination contribute to excessive use of alcohol (Ebbett & Clarke, 2010).

A positive association between alcoholism, substance abuse and smoking and increased risk of delayed TB diagnosis is recognized (Storla, Yimer & Aksel Bjune, 2008). In this study, substance use was strongly related to patient-delay-in-seeking-treatment in the interviews. As previously noted, many in the transmitter group described not initially being aware of their symptoms due to their substance use or believing their symptoms were due to their substance use.

Although these factors were not explicitly mentioned in the interviews high substance use is associated with TB treatment compliance and malnutrition (Lonnroth et al., 2009; Munro et al., 2007). These other social determinants of health may contribute to increased rates of TB and disease transmission.

6.2 Delay in Receiving Tuberculosis Diagnosis

Delayed diagnosis of TB is considered a problem in industrialized countries (Greenway et al., 2002). Increased time without receiving proper treatment may result in greater patient morbidity, mortality and spread of TB in the community (Greenway et al., 2002; Gundersen Storla, Yimer & Aksel Bjune, 2008). It has been estimated that an untreated smear positive patient may infect on average “more than ten patients annually and over twenty during the natural course of untreated disease until death” (Guled Farah et al., 2006). Most transmission occurs between the onset of cough and the initiation of treatment and therefore early initiation of treatment is crucial (Gundersen Storla, Yimer & Aksel Bjune, 2008).

In this thesis, diagnosis delay was self-identified by the participants on the survey as the time between the onset of symptoms and receiving a TB diagnosis. Delayed diagnosis may occur due to patient delay in seeking treatment or healthcare delay in diagnosis. Delayed diagnosis due to health care delay has been attributed to the relative rarity of the disease in some areas resulting in lack of experience and expertise in recognizing, diagnosing and treating TB (Greenway et al., 2002). In this study both the Canadian transmitters and non-transmitters had experiences with health-care delayed tuberculosis diagnosis in that a number of participants received other diagnoses and subsequent treatment regimes that did not properly treat their symptoms prior to receiving a TB diagnosis. Participants of both groups described receiving initial diagnoses of pneumonia or bronchitis upon visiting a physician and receiving ineffective treatment. For some participants, it took several visits to their physician and several experiences with the wrong treatment in order to get an appropriate diagnosis of TB and initiation of TB treatment. A female in the transmitter group told her doctor she had been in contact with someone with TB, even though she had not been, so that her doctor would test her for tuberculosis. In New Zealand, health-system delays are identified as contributing significantly to overall TB diagnosis delay (Calder, Gao & Simmons, 2000). One participant in this study, Pita, was given a diagnosis of psychosis without the doctors inquiring about his health history and current symptoms. Upon his

TB diagnosis, he was taken off his psychosis medication. Another health system delay occurred when a doctor did not consider TB as a diagnosis initially.

In this study, individuals in the Canadian transmitter group had a substantially greater self-identified delay between onset of symptoms and tuberculosis diagnosis than those in the non-transmitter group (five months compared to one-and-a-half months). There is not a universally accepted time of acceptable delayed-diagnosis. Some authors believe that the delay-time between symptoms and initiation of treatment should not exceed one month, while others believe that a period of less than two months is acceptable (Guled Farah et al., 2006). In this study, the average delayed diagnosis time of the transmitters was beyond two months. All participants in the transmitter group, except for one had a time between symptom onset and TB diagnosis of greater than two months. The transmitter with the shortest time period was the female at four weeks delay.

The greatest distinction between the transmitter and non-transmitter group was in patient-delay-in-seeking-diagnosis and there was a strong association with substance use, based on the information that emerged from the interviews. As previously reported, those in the transmitter group spoke heavily of the influence of substance use on the recognition of their TB symptoms. Many felt their sickness was due to drinking or smoking and felt they may go away in time.

Although the time period between initiation of symptoms and treatment seeking was not known in the Maori or Pacific experience of TB, nor was it explicitly mentioned in any of the interviews, delayed diagnosis, both patient and health-care diagnosis, is a significant factor associated with tuberculosis in New Zealand. Hay, an Auckland physician and whose experiences with her dissertation around tuberculosis contributed information to this study, noted that, in her opinion, delayed diagnosis was the number one factor associated with continued TB transmission (Hay, personal communication, September 2010). It has been observed that health-system delay contributes more to diagnosis delay in New Zealand than patient-delay (Calder, Gao & Simmons, 2000). In relation to system delay, the same study noted that the first consulting doctor did not often perform an x-ray, inquire about TB history or obtain a sputum smear, despite patient's presenting with classical TB symptoms (Calder, Gao & Simmons, 2000). Factors associated with patient delay included patients who smoked, patients who reported cough, those who hoped their symptoms would just disappear and those who feared a diagnosis.

Delayed diagnosis due to health-system delay is believed to occur less frequently for Pacific people as they are viewed as an ethnic group most likely to contract TB and therefore TB is considered almost immediately when Pacific patients present with TB-like symptoms (Ng Shiu, 2006). Ng Shiu stated that some of the Pacific participants she interviewed with pulmonary tuberculosis had a delay in seeking medical attention. Despite their symptoms of cold sweats, loss of weight, loss of appetite and persistent cough, they delayed seeking health attention until they could no longer handle the pain (Ng Shiu, 2006). For some, this delay was several months and could therefore have contributed to transmission of the disease. For two of the patients who delayed seeking medical treatment, Mateo and another individual whose interview I did not have access to, this delay led to transmission of the infection to children within their household (Ng Shiu, 2006).

Quantitatively, it has been shown that a total treatment delay of greater than ninety days was associated with an increased number of contacts with TB (Golub et al., 2006). Contacts of undiagnosed cases are at increased risk of acquiring a TB infection and becoming a future case and therefore identifying TB cases and limiting the number of contacts an infectious person has is an important component of controlling TB transmission (Golub et al., 2006).

6.3 Number of Contacts

As tuberculosis is an infectious disease the number of close contacts an infected individual has will influence the number of people that will potentially become infected as a result. In this study, those in the transmitter group had an average of forty-two close contacts while those in the non-transmitter group had twelve. The number of contacts an individual has is associated with an individual's living conditions, work environment and social network and is connected to the amount of time infectious. Throughout both the Canadian and New Zealand interviews, individuals spoke about acquaintances and relationships and their social activities prior to TB diagnosis that may facilitate increased disease transmission (ex. increased number of family members living in house, living in work camps, hitch-hiking and enjoying social visits).

Another factor associated with the number of contacts an individual has is housing conditions such as crowding. A study by Clark, Riben & Nowgesic (2002) found a significant association between housing density and rates of TB. A study by Larcombe et al. (2011) reported that the number of square feet per person in a house was the most significant factor associated

with the presence of tuberculosis. In this thesis transmitters lived in accommodations with housing densities of 0.67, 2.25 and 2.4 (average = 1.8). The housing density was not available for two within the transmitter group as one individual was homeless and one lived in a shared accommodation. Those in the non-transmitter group lived in accommodations with housing densities of 0.6, 0.67, 1 and 2.14 (average = 1.1). The housing density was not available for one individual as they lived in a shared accommodation. Although the sample is limited and there is no statistical comparison of significance, the transmitter group had a greater average housing density. It is also important to note that the transmitter with the lowest housing density (0.67) was also the transmitter with the least transmission points (7 points) and the non-transmitter living with the greatest housing density (2.14) was also the non-transmitter with the greatest number of transmission points (3 points).

The information around housing was also limited due to the transient nature of Aboriginal people. In Canada, Aboriginal people relocate more frequently than non-Aboriginal people for a variety of reasons including family motives, employment opportunities, housing, health care, training and education (Carter & Polevychok, 2004). As a result, the number of people a study participant identified as living in the same accommodation may not accurately reflect the average number of people who stay in the accommodation. Similarly in New Zealand, transience occurs and housing characteristics change more frequently for Maori and Pacific households than for Pakeha households (Johnson, 2002; Peace & Kell, 2001).

Substance use was a distinguishing factor between those in the Canadian transmitter group and those in the Canadian non-transmitter group. The visual representations created highlight one of the proposed mechanisms through which substance use may ultimately affect increased transmission; namely the connection between substance use, patient-delay-in-seeking-treatment and number of contacts. These factors were relevant for those in the non-transmitter group as well but were greater in magnitude for the transmitters, potentially explaining the increased transmission. However, increased transmission may not be explained solely by this connection. These factors are not isolated nor are only connected with one another. These social determinants of health are influenced by and influence other social determinants of health that may have contributed to increased barriers to accessing health care and an increased risk of tuberculosis and tuberculosis transmission. The following section of the discussion explores additional social determinants of health that, based on results from both this thesis and other

literature, may be associated with the three identified factors (substance use, patient-delay-in-seeking-treatment and number of contacts) and increased risk of tuberculosis.

6.4 Stereotypes as Barriers to Accessing and Receiving Health Care

Substance use may not only affect disease, specifically tuberculosis and transmission directly, but also may affect other determinants of health. A 2005 study found that cultural stereotypes regarding Aboriginal people were relevant to practicing nurses in regards to their interactions with Aboriginal patients and these stereotypes influenced their perceptions and treatment of Aboriginal patients (Browne, 2005). “The image of the ‘drunken Indian’ is one of the most enduring colonizing images pervading Canadian society” (Furniss, 1999 in Browne, 2005), and many nurses were aware of the fact that a number of their Aboriginal patients dealt with complex social situations, including alcohol and substance abuse, and therefore, the nurses often equated these problems as cultural problems representative of all Aboriginal people. Often, when faced with a large number of people from a certain cultural group who suffer from a certain issue, including substance use, it is a challenge not to then believe that it is a cultural characteristic or a situation that all people within the cultural group deal with. This in turn can result in judgments and affect a health professional’s interactions with all patients they see from specific cultural groups (Browne, 2005). One Alberta transmitter, Robert, noted that during one interaction with his doctor, he felt the doctor was just prescribing medication without truly inquiring about his symptoms and the underlying problem because the doctor thought Robert was just in the hospital to receive drugs for recreational use, not for treatment of a real health issue. Numerous studies recognize the consequences of health professionals relating to patients based on assumptions and stereotypes. This action can have serious negative consequences as to the quality of health care received and can “jeopardize the delivery of equitable, effective services” (Anderson et al., 2003; Browne, 2005; Browne & Fiske, 2001).

Additionally, other culture based stereotypes may affect an individual’s motivation to seek treatment as well as their experience with treatment. These may be experienced regardless of behaviours around substance use and may be relevant for both those in the transmission group as well as in the non-transmission group in Canada and in the New Zealand Indigenous experience. In the Canadian study, all participants had smear positive pulmonary tuberculosis and the potential to transmit and stereotypes surrounding Aboriginal people and stigma

associated with tuberculosis may impact all tuberculosis patients with their health seeking and treatment behaviours. For those in the transmitter group, the high substance use and the additional stereotypes and social issues that come-along with substance use may add another layer of social issues surrounding their tuberculosis experience that ultimately result in increased transmission. Robert feared that if he called in sick to work his employers would automatically think it was due to substance use. He felt they were just looking for reasons to fire Aboriginal people and he did not want to give them a reason to fire him. The perceived prejudice he experienced by his employers limited his ability to seek care, contributing to the barriers associated with cultural based stereotypes.

Elliot and Leeuw (2009) describe a situation in which a physician lack-of-understanding and appreciation for a patient's beliefs and history can create barriers and misunderstandings that can potentially be fatal. In describing a course of treatment for an Aboriginal woman that included isolation, the physician was not aware of the woman's perceptions of tuberculosis and isolation stemming from a context that included sanatoriums from which many never returned. The woman therefore exhibited extreme fear and anxiety with the treatment regimen being presented. The doctor was not aware of the history of tuberculosis in the community or the relevance that such history brings into the contemporary experience and was initially perplexed by the woman's reaction (Elliot and Leeuw, 2009). They note that medical students are taught that Aboriginal people in Canada have poor health and lower standards of social and economic conditions and often this results in doctors equating "being Aboriginal" with poverty, crime and other depressed social conditions. Blame is often put on patients for having the disease or for being homeless, being a substance user or being part of poor social conditions, factors contributing to health status (Burke, 2011). As a result, many in the health profession will attribute poor health to cultural groups, not socioeconomic ones (Elliot & Leeuw, 2009). Several additional studies have noted a pattern of blaming Aboriginal people for their health problems, not recognizing and considering the historical and social processes that have resulted in contemporary situations (Elliot and Leuw, 2009; Kelm, 2001; Tait, 2000; Towle, Godolphin & Alexander, 2006). In a study examining Inuit experiences with TB in Nunavut, Canada, participants felt that colonial experiences were not just historical. Many noted feelings of disrespect and patronization when interacting with their current health care providers (Moller, 2010). Health care providers did not explain why patients were meant to take TB treatment and if

they experienced difficulties with their treatment and stopped taking it, they were contacted by the police. These experiences, lack-of-communication, and lack of understanding from health care providers can do great harm in creating distrust and increasing barriers that ultimately discourage people from seeking health care.

Although no Maori or Pacific participant in this study explicitly described feeling that they were discriminated against or received poor health treatment because of their ethnicity, stereotypes towards Maori and Pacific people exist in New Zealand and have been recognized in other literature. Discriminatory language towards Maori people that contribute to the construction of stereotypes is used extensively in New Zealand (Cotter, 2007). Discriminatory language containing racist undertones is found in many domains of life including education, politics and health, enforcing and strengthening negative Maori stereotypes. As a consequence Maori people as a group are associated with these stereotypes (Cotter, 2007). A case-study examining Maori experiences in New Zealand hospitals found that Maori people are often marginalized within mainstream health services and that their experiences influence their decisions and desire to leave the hospital as soon as possible (Barton, 2008). Another study in New Zealand noted that Maori patients reported the highest prevalence of racial discrimination in their hospital experience, which has been established as a social determinant of health in New Zealand (Harris et al., 2006).

Stereotypes and perceptions surrounding tuberculosis are also relevant in this thesis and may impact health seeking behaviours, ultimately leading to increased tuberculosis transmission. Tuberculosis has become identified with its risk factors and as a result, tuberculosis, homelessness and substance use become interchangeable, resulting in discrimination (Burke, 2011). Some Maori individuals experienced social exclusion due to their experiences with tuberculosis. Rangi was asked to leave his rental accommodation once he returned from the hospital following his TB diagnosis and treatment and Ngaire felt that people feared her when she went back to work, despite being declared as no longer being infectious and cleared by a physician to go back to work. Additionally, the partner of Kowhai felt ostracized by her family because her partner had TB, despite herself testing negative for TB. Another patient felt discriminated against in regards to his TB in the hospital in that the non-medical hospital staff treated him differently and avoided cleaning his room. These experiences may deter people from identifying themselves as TB patients and seeking out health care in the future if their TB returns

or if they have complications. It could also deter them from continuing their treatment, which is a long-term commitment. Additionally, hearing of the existence of negative repercussions due to TB could deter future potential TB patients from seeking out health care and identifying themselves, potentially increasing their infectivity and transmission of the disease.

The fear of TB for the Pacific participants stemmed from the historical experiences of TB. Some participants noted how they remembered how TB patients were treated on Samoa in terms of isolation (Ng Shiu, 2006). Sarah, a woman from Tuvalu, recalled a missionary nurse on the Island who described TB as being ‘scary’. As a result, when her son was diagnosed with TB she initially was scared although she subsequently felt better upon learning there is a cure (Ng Shiu, 2006).

In Canada, David noted that he believes that within his community, when people think of TB they think of historical and negative aspects of TB, which may deter them from identifying themselves as a TB patient or seeking treatment. Other participants in the Canadian context believed that there would be less fear associated with TB if people were more open about it and commented on how it is hard to get people to talk about their experiences with tuberculosis. The majority of individuals in the transmitter and non-transmitter group, and in New Zealand, commented on how they knew very little about the disease. Some were aware of historical aspects of the disease but felt they may have inquired about their symptoms earlier if they knew more about the disease and the importance of early treatment. Rebecca noted that she believes her community needs someone to stand up as a role model and discuss their TB in order to educate and encourage people to talk about TB so they are aware of the symptoms to look for and the importance of seeking-treatment. Other literature has identified limited awareness and understanding around TB, TB symptoms and importance of seeking treatment as a barrier to seeking health treatment and associated with increased risk of diagnosis delay (Brassard et al., 2008; Macdonald, Rigillo & Brassard, 2010; Gundersen Storla, Yimer & Aksle Bjune, 2008).

6.5 Family and Social Networks

A theme resonating in the non-transmitter group was that of support. The males in the non-transmitter group commented on their independence and self-described as being “loners”. Additionally, the males commented on their habits of dealing with life situations, including health and illness, on their own and “waiting-it-out” until things are better. Conversely, the two

females in the non-transmitter group emphasized the importance of family and support networks. The two females noted their fear of transmitting the disease to their family and friends and discussed the significance of their family in terms of support, healing and motivation to get better. Despite the females in the non-transmitter group receiving multiple other diagnoses prior to TB diagnosis and feeling lonely in the hospital, the support from their family and desire to get better so they could return home to their family acted as motivation to get better. Family support was experienced differently by the Maori and Pacific participants but some noted the positive support from family and friends and how it acted as motivation to remain in hospital on treatment until given approval to leave. For one Maori woman, the support of her partner was significant in her determination to stay in the hospital and receive her full course of treatment despite negative experiences with her physicians.

Other studies have noted the importance of family and family life for Aboriginal women and their concern with protecting their family (Stout & Kipling, 1998). Traditional views on children also note that children are gifts from the creator and that they bring love and respect to families (Aboriginal Family Healing Joint Steering Committee, 1993). One female in the non-transmitter group also commented on the importance of educating her family as to her TB experience to ensure that if they ever become sick with TB symptoms they will recognize them and understand the importance of seeking health care.

Many of the New Zealand interviewees noted the importance of support from their public health nurse. Many had a strong relationship with their PHN who helped them navigate the health care system and their treatment schedules. A study by Searle, Park & Littleton (2007) noted the importance of the public health nurse. Although that study was looking at tuberculosis treatment experiences for older Pakeha people in Auckland, similar to the results of this study for the Maori and Pacific people, the PHN provided support and was a key person in patients' support networks (Searle, Park & Littleton, 2007).

6.6 Social Determinants of Health

The discussion thus far has highlighted the social determinants of health identified in this study, and in relation to other relevant literature, pertaining to tuberculosis and increased transmission based on Indigenous experiences of TB in both Canada and New Zealand. The discussion has included information around a potential pathway of association from substance

use to increased transmission that emerged as relevant for the Aboriginal transmission group. Additionally, the discussion noted that the identified factors are not isolated and may influence other social determinants of health that in turn influence rates of tuberculosis and transmission. The following section of this chapter examines the importance of not only considering social determinants of health when exploring causes of disease but also considering the origins and causes of such determinants.

Many studies exploring the determinants of Indigenous health recognize the social determinants of health and the role of social inequality, stress, poverty, and unemployment, etc, as significantly contributing to poor health outcomes (Macdonald, Rigillo & Brassard, 2010). However, recognition of these determinants and their relation to health alone is not sufficient. Although focusing on these determinants is important, what is often overlooked in analyses of social determinants of health are what Marmot (2005) would refer to as the ‘causes of causes’, in this case, a colonization history and ongoing racism. To successfully decrease the rates of TB within Indigenous communities and decrease the disparity of the disease between Indigenous and non-Indigenous people, the “causes of causes” must be addressed (Marmot, 2005). After successfully controlling a TB epidemic in New York and Chicago without adequately addressing the causes of the epidemic it was said that “the success of the fight against TB was at best a partial one, because it did not address the roots of tuberculosis and the soil in which they grew” (Draus, 2004). It has also been said that the lower-standard of living and lower health status of colonized people, such as Aboriginal people in Canada, and Maori and Pacific people living in New Zealand, compared to colonizers will remain the same until decolonizing programs and policies are implemented (Dei et al., 2000; Smith, 1999) and that the failure to recognize history and social context is one of the biggest limitations in tuberculosis control programs (Burke, 2011). Elliott and Leeuw (2009) describe how medical students learn the strong connection between social determinants of health and Aboriginal health in that “they have poor health status and experience substandard social and economic conditions”. However, few are ever taught or recognize the historical and social contexts that give rise to the contemporary social determinants of health.

The analysis of the Canadian Aboriginal interviews was guided by the Assembly of First Nation Wholistic Policy and Planning Framework (figure 3.1, p. 30) and the NAHO list of the social determinants of Aboriginal health (chapter 3, p. 28). The AFN framework considers not

only social indicators of health and wellness that would be found in a non-culture specific social determinants of health framework but also includes cultural specific components of health ensuring that analysis of the social determinants of health is not in isolation and that the “causes of causes” are addressed. The additional determinants specifically outlined in the NAHO list of social determinants increases the focus of culture specific determinants of health, recognizing the importance of colonization and historical processes when understanding current health and indicators of Aboriginal health. Wilson and Rosenberg (2002) note that although there is a large body of research that attempts to explain health inequities, few do so by incorporating First Nations peoples’ culture into their analysis. The framework acknowledges the historical processes of colonization and a holistic view of health in which spiritual, emotional and mental factors are included as indicators of health, congruent with Aboriginal traditional views and the Medicine Wheel.

Substance use, patient-delay-in-seeking-treatment and contacts can be placed within the indicators of community health and wellness seen in the second most outer ring of the framework (fig. 3.1, p. 30). The analysis of this project revealed connectivity between health factors and this was discussed previously in this chapter. Substance use is not an isolated behaviour and is often linked with other factors. Increased substance use is both influenced by, and influences other indicators of health and health behaviours. Studies exploring substance use within Aboriginal people have associated increased substance use and the negative resulting outcomes with colonization (McCormick, 2000). Individuals have turned to alcohol and other substances as a coping mechanism. This analysis also noted the connection between substance use and stereotypes associated with substance use that may influence health professional’s judgments and interaction with patients. These actions increase the barriers that impact a patient’s ability and likelihood of seeking health care. Additionally, some individuals noted the connection between contemporary experiences of loss of traditional land and government control with decreased participation in traditional activities and increased drinking habits.

This thesis project revealed that factors associated with increased tuberculosis transmission, resulting in increased disease incidence, are not isolated factors. As previously mentioned, the public health threat of tuberculosis has less to do with understanding the disease and treatment biomedically, and more to do with the failure to understand it in terms of historical and contemporary social determinants of health. The results of this study highlight the

complexity and connectivity between social determinants of tuberculosis transmission and that the roots of the social behaviours can be traced to the destructive processes of colonization that affected many aspects of Indigenous people's lives, in both Canada and New Zealand. Scholars across many areas of Indigenous health research agree that the continued disparities in health and social status are entrenched in colonization and the historical relations between Indigenous people and government (Adelson, 2005; Browne, 2005; Dion Stout, Kipling & Stout, 2001; Levien, 2007). The health status of Aboriginal people within Canada has been compared to the health situation of developing countries (Adelson, 2005). The complex history associated with colonization, including colonial politics, policies and practices has resulted in intense social and cultural disruption in many Canadian Aboriginal communities (Browne, 2005). As a result, communities and their people have been forced into economic dependence upon the government. The government has enacted several regulations upon Aboriginal peoples' lives and these restrictions have shaped Aboriginal people's life opportunities, economic conditions, overall health and the social status of individuals, families and communities (Browne, 2005).

One female Aboriginal participant in this study noted that, in relation to TB, individuals in her community need role models. They need someone to step up, discuss their experience of TB and provide guidance and direction for other members of the community. Individuals need not only education in relation to tuberculosis but also opportunities that will empower individual people to not only encourage them to share their experiences with tuberculosis but also their other life experiences and overall help them make more positive life choices.

There are numerous programs that target Aboriginal people that look to increase opportunities for youth, adults and their families. Programs such as *Warrior Spirit Walking* in Prince Albert, Saskatchewan, the *Regina Anti-Gang Service (RAGS)* in Regina, Saskatchewan and the *Ghost River Rediscovery* program in Calgary, Alberta, among others, are opportunities meant to increase Aboriginal people's autonomy, self-belief and determination and help decrease the numbers of Aboriginal people involved in criminal and gang activity and substance use. Additionally, they aim to increase the number of students who complete their education, seek higher education and obtain successful employment. These programs look to address specific determinants of health but also look to help individuals increase self-determination, autonomy, empowerment and cultural awareness and respect, representing many of the characteristics colonization and its long-term effects have impacted. Although the organizations may differ in

their specific programs offered, the long term goals are similar: restore the imbalance of life for Aboriginal people that stems from colonization, residential schools and the multi-generational effects, increase positive opportunities for Aboriginal people and decrease the disparity in social determinants of health.

Like the AFN framework of health, the *Whare Tapa Wha* model, a Maori model of unified health focuses on a holistic view of health. The *Whare Tapa Wha* model of Maori health was developed as means of recognizing that a holistic framework which addresses concepts beyond the biomedical was necessary for promoting and evaluating Maori health. The four realms of the model are physical health, emotional health, spiritual health and social health. The results of this study highlight the social determinants influencing the tuberculosis experience can be placed within and across these four areas. In his paper describing the development and applications of the model, Rochford (2004) outlines how the *Whare Tapa Wha* model can be used to understand type 2 diabetes mellitus for Maori people (figure 6.1, p.116).

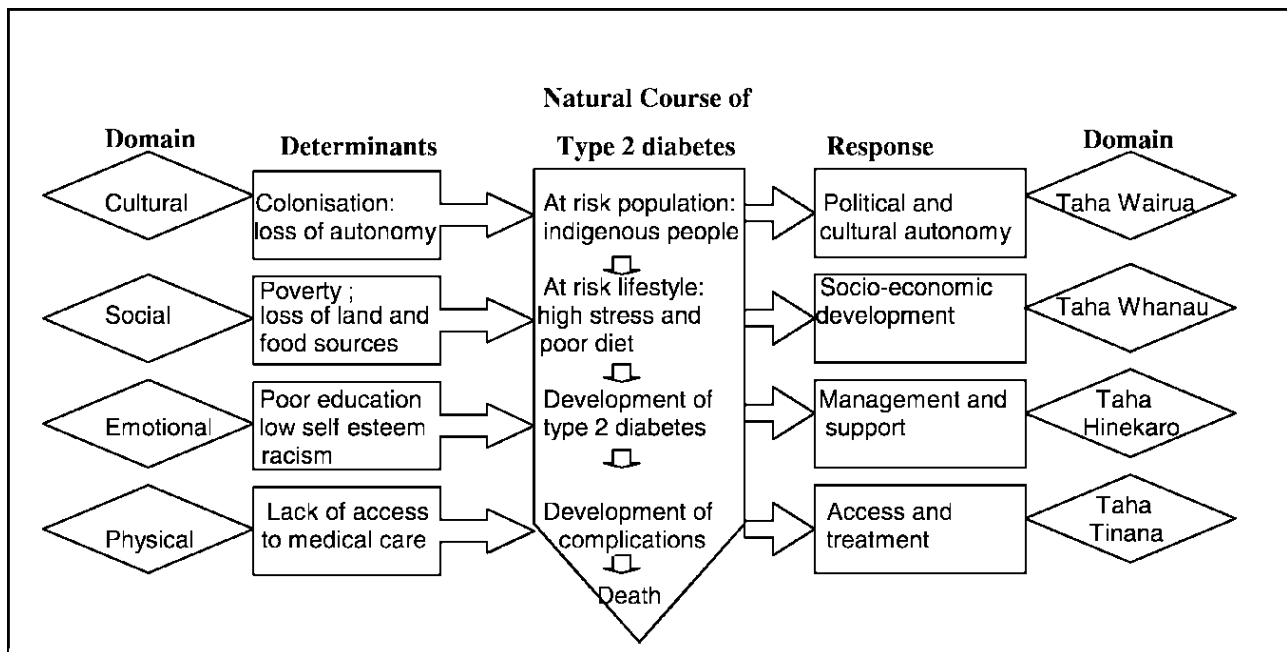


Figure 6.1: The *Whare Tapa Wha* model and Maori experiences with Type 2 Diabetes (Rochford, 2004).

Figure 6.1 outlines how exploring the experience of diabetes within the *Whare Tapa Wha* model provides a holistic view of the experience, recognizing not just the immediate social determinants of health, but also the causes of colonization that are often not recognized in studies

analyzing social determinants of health (Macdonal, Rigillo & Brassard, 2010). The pathway explores health solutions and responses that do not just focus on biomedical aspects but address all domains of Maori health (Rochford, 2004). The same understanding is necessary for tuberculosis. The analysis of this study highlighted a number of social determinants of health relevant in the Maori experience of tuberculosis that have been previously discussed in this chapter. Using the *Whare Tapa Wha* framework allows one to recognize the multiple domains in which those factors fall, the connectivity between them, and their origins in colonization, loss of autonomy and economic sustainability and the long-term effects of such experiences on health, education, employment, etc.

The Pacific framework of health is based on a general Polynesian perspective of holism and health (Capstick et al., 2009; Ng Shiu, 2006). Within this view, health and wellness is not solely based on biomedical aspects of health but also includes the role of community and family (Ng Shiu, 2006) and the place of tradition and the role of spirituality and religion (Capstick et al., 2009). Although the Pacific interviews I had access to were limited in both detail and in numbers, the information from the interviews alludes to social and cultural determinants of health. Similar to the Aboriginal and Maori frameworks of health, understanding the emergent social determinants of health within a holistic view of health highlights the connections between health determinants and increases the awareness for solutions that address such factors and their root causes.

A study of Inuit experiences with tuberculosis noted that “life struggles seemed to overshadow the concern about TB or compound the struggle with the disease in some cases” and that many of the life struggles were linked with the results of colonization (Moller, 2010). The analysis in both Canada and New Zealand of Indigenous experiences with TB noted similar results. Participants faced numerous daily struggles that compounded their experiences with TB and their ability to seek health treatment. Both Hay and Oh noted that their TB participants were often part of the most vulnerable and marginalized population groups and daily life situations increase the struggles and complexities for them such that responding to or dealing with health problems, including tuberculosis, cannot or may not always be a priority.

6.7 Strengths and Limitations of Project

In looking at just the Canadian component of the project, the analysis was limited due to the number of TB participant's interviews and surveys available to draw on. This limited the use of the quantitative survey data to descriptive statistics only. There are additional interviews and surveys to analyze from Manitoba and Saskatchewan and this will occur in the future. By increasing the number of participants within the sample, logistic regression will be done to statistically analyze the predictors of tuberculosis transmission. Factors tested in the logistic regression model will be informed by the results of this study and through consultation with the investigators of the *Determinants of Tuberculosis Transmission* project. Additionally, interpretive phenomenological analysis will occur on the added interviews to increase the support for the emergent themes from this study as well as highlight additional themes that surface in those contexts.

While I had initially intended to compare experiences of tuberculosis transmission and non-transmission in populations Indigenous to Canada and New Zealand (given the similarity in colonization history), there was insufficient information available about the New Zealand interviews and participants to create comparative groups as I had done in Canada. Nevertheless, there was still abundant information regarding the Maori and Pacific people's experiences with tuberculosis available that I was able to access and analyze. I was therefore able to compare the overall TB experience of Maori and Pacific people with the experiences of transmission and non-transmission in Alberta Aboriginal peoples. The analysis of secondary data from many researchers and projects in New Zealand was successful in identifying common and unique experiential threads. I am cautious, however, in making direct comparisons across cultural groups.

The detail of the responses of the Pacific TB participants I had access to was very limited. This in turn limited the analysis and interpretation that could occur. The results presented in the thesis may appear to focus more on Maori experiences of TB and this is not necessarily a reflection of greater relevance of social factors for Maori experiences of health but is due to the limitations in available data for Pacific TB participants. The student who conducted the interviews with the Pacific patients also faced barriers and limitations in her work that have therefore had an influence on my work.

A strength of the study and a strong methodological contribution of this work is that of the secondary analysis of qualitative data. In both contexts, the interviews which I accessed included a wide range of questions related to tuberculosis experience and were meant to be used in a variety of smaller projects. I was not able to develop the interview plans based on an interpretive phenomenological study focused solely on tuberculosis transmission. Moreover, as I was not involved in the interview process, I did not have my own field notes to supplement the interviews. Despite this limitation, the information available did allow for a thorough analysis of the twenty-one interviews with Indigenous peoples experiences with TB. In Canada, I was able to view the field notes of the interviewer and listen to the audio recordings and in both contexts I was able to speak with the interviewers. This supplemental information furthered the ability and success of identifying common and unique experiences of TB within and between cultures.

6.8 Conclusion

Tuberculosis transmission is not yet completely understood from both a biomedical and social perspective. There are many factors that influence the rate of transmission including those of the infected individual, the environment, and of the potential new infected case. In relation to the first research objective of comparing Aboriginal individuals from Alberta diagnosed with smear-positive pulmonary tuberculosis identified as having many transmission events to Aboriginal individuals from Alberta also diagnosed with smear-positive pulmonary tuberculosis but who have not been linked to transmission events, this study identified different social circumstances between the two groups. Substance use, patient-delay-in-seeking-treatment and number of contacts were of greater relevance for those in the transmitter group and the relationship between these three factors may contribute to increased rates of tuberculosis. These factors are also associated with other social determinants of health that may influence increased rates of tuberculosis transmission. In relation to the second research objective of exploring the experience of tuberculosis for Maori and Pacific people in New Zealand and comparing the relevant social determinants of health to the results from the Canadian context the three identified factors are relevant within the tuberculosis experience for Indigenous people in New Zealand and may contribute to increase transmission events similar those in Canada.

Additionally, this study highlighted the complexity of understanding tuberculosis within Indigenous populations. In two countries, and in two groups of unconnected people, Aboriginal

people in Alberta, Canada and Indigenous people in New Zealand, who only share a similar historical experience of colonization, tuberculosis occurs at a much higher rate than in the non-Indigenous people of both countries. Examining the disease experience within culture specific health frameworks identified the importance of considering the “causes of causes” when exploring the determinants of tuberculosis and factors associated with transmission. Stemming from the experiences of colonization, high rates of tuberculosis can be considered an indicator of something greater. Social circumstance is a key component in understanding the high rates of tuberculosis for these Indigenous people. Aboriginal people in Canada and Maori and Pacific people in New Zealand experience high rates of poverty, low education, unemployment and poor housing compared to their non-Indigenous countrymen. However, looking solely at these proximal social determinants of health is not enough to fully understand the disparity in disease rates. These social circumstances are rooted in similar experiences of colonization, disempowerment and continued racism and thus high rates of TB, and other diseases, may be seen as an indicator of such experiences.

Historical research notes that not only did the rates of tuberculosis increase through direct contact with Europeans, but the increase was also strongly influenced by economic and sociocultural changes (Daschuk, Hackett & MacNeil, 2006). These changes disrupted the traditional way of life for people, increasing stressful and negative social circumstances that contributed to the high transmission of the disease. Such negative social circumstances, though not necessarily identical to the historical situation, persist and facilitate the continued transmission of tuberculosis. Maria Linklater, an Elder from Saskatchewan, has noted that colonization has resulted in a loss-of balance for Aboriginal people and this has contributed to individuals making poor life choices, ultimately leading to negative consequences including poor health. She states that when a person knows who they are, when they are physically, mentally, spiritually and emotionally balanced, that is when an individual is healthy and will make healthy life choices (Roberts, 2002). Similarly, disempowerment can be seen as the link between experiences of colonization, a history of cultural oppression and contemporary circumstances. Colonization processes including, oppression, acculturation and loss-of-land have resulted in disempowerment and a loss-of cultural identity (Frolich, Ross & Richmond, 2006; Kirmayer, Simpson & Cargo, 2003; Richmond & Ross, 2009). Warry (1998) states that contemporary social disparities and sufferings are attributed to not only economic suffering but also low

cultural esteem and lack-of-identity, conditions stemming from a history of oppression and marginalization. Future research and programs must focus on mechanisms of empowerment for both individuals and communities as a means of decreasing disparities. The historical processes and contemporary conditions cannot be ignored and literature has noted that although it is important to recognize and address the proximal social determinants of health, research, education and programs cannot ignore the “causes of causes”. In a recent study looking at colonization as a broader social determinant of health, specifically a determinant of Indigenous mental health disparities, Czyzewski (2011) noted that:

Colonialism is the guiding force that manipulated the historic, political, social, and economic contexts shaping Indigenous/state/non-Indigenous relations and account for the public erasure of political and economic marginalization, and racism today. These combined components shape the health of Indigenous people.

Future initiatives must focus on means of addressing such marginalization and racism and on restoring balance, cultural awareness, self-determination and autonomy and community self-dependence and economic dependence in the process of addressing the more proximal social determinants of health that ultimately contribute to wellness.

Despite advances in the biological understanding of the bacterium *M. tuberculosis* and subsequent treatments, tuberculosis continues to be a burden for Aboriginal people in Canada and the Maori and Pacific people in New Zealand, and the disparity in the rates between Indigenous and non-Indigenous people persists. Together, the analysis of Indigenous experiences of tuberculosis has highlighted the unique social factors associated with TB, the connectivity of these factors and the complexity of life for the participants. Despite the cultural differences between the Canadian and New Zealand Indigenous populations, the comparative history and similarity of circumstances created an opportunity to explore the commonalities and differences in tuberculosis experience. This thesis contributes to the understanding of the social determinants of health as well as highlights the need to recognize the causes of the social determinants of health and the necessity for continued research, education and program planning that centers on both proximal and distal social determinants of health as a means of reducing, among other things, high rates of tuberculosis for Indigenous people.

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APPENDIX I

QUANTITATIVE QUESTIONNAIRE (Created by the DTT project group)

In-person data collection form

1. Details of interview

To be filled out by interviewer:

1.1 DATE

--	--	--	--	--	--	--	--

 (yyyy/mm/dd)

1.2

LOCATION: _____

(Province, Community and location type, e.g. clinic, hospital, health centre, other)

1.3 DURATION: **Start Time** (24 hr)

 :

clock

Stop Time (24 hr)

 :

clock

1.4 ATTENDEES: (number)

--	--	--

 (other than participant and interviewer)

	Name		Relationship
1.	_____		_____
2.	_____		_____
3.	_____		_____
4.	_____		_____

1.5 COMPLETED y n aborted

If ABORTED, indicate reason _____

1.6 PATIENT STUDY NO.

--	--	--	--	--	--	--	--

1.7 PHIN/PHN: _____

1.8 PATIENT DATE OF DIAGNOSIS: _____

(yyyy/mm/dd)

(start date of treatment)

1.9 PATIENT NAME _____

1.10 GENDER

F M

1.11 DATE OF BIRTH

--	--	--	--	--	--	--	--	--

(yyyy/mm/dd)

2. General Information

2.1 Are you married, common-law, single, etc?

- Married
- Single
- Divorced
- Separated
- Common-Law
- Widow
- Other _____

2.2 Are you a student? y n

2.3 What is the highest level of education that you have? (read options)

- High School Diploma y n **If no,** grade completed _____
- Attended College (non-trade) y n
- If yes,** Certificate/diploma obtained y n
- Attended College (trade) y n
- If yes,** Certificate/diploma obtained y n

Attended University y n

If yes, Degree obtained y n

2.4 Were you working up until you got sick? y n

If yes:

Where? (job title and location)

Is your work mainly indoors & outside your home? y n

Does your position require travel? y n **If no, go to 2.5**

If yes, where to and how often (weekly, monthly, daily)?

If no:

Have you been employed during the last year? y n

Are you retired? y n

Are you on social assistance? y n

Are you disabled?

Temporary y n

Permanent y n

2.5 Are you of Aboriginal heritage? y n **If no, go to 2.6**

If yes:

Treaty

Non-treaty

Métis

Inuit

2.6 **If Aboriginal:** What band are you affiliated with? _____

Is that in Alberta (MB/SK)? (If no, where?)

2.7 What is your mother tongue (first language)? _____

Linguistic Group (if Aboriginal): (See Appendix I for classifications)

2.8 Are you fluent in an Aboriginal language? y n

2.9 Were your parents born in Canada? y n **If yes, go to Section 3**

If no: Where are they from? _____

3. Health Issues

3.1 Is this the first time you have been sick with TB? y n
(active TB *not* latent)

3.2 To your knowledge, have you ever been a contact of someone who had TB? y n

3.3 Have you ever had a transplant (Immunosuppressant therapy)? y n

3.4 Are you taking medication that your doctor or nurse told you could weaken your immune system? y n **If no, go to 3.5**

If yes: Specify _____

3.5 Do you have any ongoing health problems that require you to see a health professional regularly (e.g. diabetes, kidney disease, silicosis, etc) y n **If no, go to 3.6**

If yes: Specify _____

If diabetic: Type I

Type II (adult onset) insulin requiring

Type II (adult onset) **non**-insulin requiring

If non-insulin requiring (or to clarify above for any Type II):

Were you placed on insulin any time after you got TB? y n

3.6 What symptoms did you have before you were diagnosed with TB? (read options aloud)

Duration

Cough y n _____

Fever y n _____

Night sweats y n _____

Weight loss y n _____

Other (specify): y n _____

3.7 Have you ever been tested for HIV in relation to your TB? y n

3.8 Do you drink alcohol? y n

If yes: How many drinks per week? _____

If yes, in the past year:

- i. Did you find that you needed to drink more alcohol to get drunk? y n
- i. Did you find that you weren't getting drunk as quickly? y n
- ii. Have you experienced signs of withdrawal (nervousness, anxiety, shakiness, depression, headache, sweating, rapid heart rate)? y n
- iii. Did you try to stop drinking, but were not able to stop? y n
- iii. Do you usually drink more than you intend to? y n
- iv. Have you had to give up something you were interested in because of drinking? (e.g. hobby, relationship, etc.) y n
- v. Have you spent a lot of time going to get alcohol or recovering from a hang over? y n
- vi. Do you feel that drinking has caused harm to your body or mind y n

Dependence: y n (At least 3 from each of i, ii, iii, iv, v, and vi)

If no: Did you ever drink alcohol? y n

3.9 Did you smoke tobacco before you were diagnosed? y n **If yes, go to 3.10**

If no: Did you ever smoke tobacco? y n **If no, go to 3.10**

If yes: Quit date (year): _____

3.10 Do you use injection drugs? y n **If yes, go to 3.11**

If no: Have you ever used injection drugs? y n

3.11 Do you use any other drugs? y n **If yes, go to Sec. 4**

(e.g. marijuana, cocaine, acid, pills)

If no: Have you ever used any other drugs? y n

4. Access to Health Care

4.1 Who do you see first when you have a health problem?

- Traditional Healer
- Community Health Nurse
- Physician
- Other Specify: _____

4.2 Do you ever see a traditional healer? (e.g. acupuncture, naturopath, shaman, medicine man/woman, etc.) y n **If no, go to 4.3**

If yes: Did you ever see a traditional healer in relation to your TB symptoms? y n

4.3 Where do you usually see a doctor?

- Clinic
- Doctor's office
- Emergency Room
- Other Specify: _____
- On reserve Off reserve

4.4 Do you usually bring someone to help you talk to doctors or nurses? y n

4.5 Do you have a regular family doctor? y n

4.6 In your opinion, do you have adequate access to health care in your community? y n

In connection with your TB:

4.7 How long did it take between your first symptoms and being diagnosed with TB? _____

4.8 Who did you see first about your symptoms? _____

Where (e.g. clinic, hospital, nursing station, etc)? _____

4.9 Have you had another chest x-ray any time within the last 12 months (excluding one that was connected with date of diagnosis of TB)? y n **If no, go to 4.10**

If yes: where (name of hospital or clinic): _____ and when (month): _____

4.10 Were you given antibiotics at any point before you were diagnosed? y n

If ABORIGINAL and living ON RESERVE (within the 6 months prior to TB Dx), ask the following (OTHERWISE go to SECTION 5):

4.11 Does your community have a Health Centre? y n **If no, go to 4.12**

If yes: Does a doctor come to your health centre? y n

If Yes: weekly
 monthly
 other (specify) _____

4.12 Does your community have a:

- Nursing station? y n
- Community Health Nurse? y n
- Community Health Representative? y n

5. Mobility

5.1 What community do you reside in? _____

(main or usual place of residence)

5.2 What is the postal code at your place of residence?

--	--	--	--	--	--	--	--

5.3 Was this where you were staying at the time of diagnosis? y n **If yes, go to 5.4**

If no:

- where (type of accommodation) _____
- location (city, settlement, reserve, etc) _____
- and with whom (family member, friend, etc) _____

5.4 In a typical week in your community, how often do you: **(Remember indoor and >4hrs each time)**

Visit family

Visit friends

Go to bingo halls or casinos

Attend cultural events/ceremonies

Attend Church

Go to the bar

Participate in other group activities

Specify (e.g. sports, clubs, etc) _____

5.5 Can you tell me any places you've stayed, visited, or traveled in the last 12 weeks (non-medical)?

Location	Reason	# of times in last 3 mo.	Duration	Outside community/city
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>
_____	_____	<input type="text"/>	Days <input type="checkbox"/> Wks <input type="checkbox"/>	y <input type="checkbox"/> n <input type="checkbox"/>

_____ Days Wks y n

5.6 Have you been in jail any time in the last 2 years? y n **If no, go to Section 6**

If yes:

1) Name of Institution: _____

Start Date of Stay: _____ (yyyy/mm/dd)

End Date of Stay: _____ (yyyy/mm/dd)

2) Name of Institution: _____

Start Date of Stay: _____ (yyyy/mm/dd)

End Date of Stay: _____ (yyyy/mm/dd)

6. Place of Residence

Participant should answer the following questions for the place where residing for four or more weeks prior to diagnosis.

6.1 What kind of place is your residence (main or usual place of residence)?

House/condo Owned Rented Band-owned Friend's Relative's

Apartment/hotel

Shelter

Prison

Homeless

Shared accom: _____

If shared accommodation:

Do you share a room? y n

Do you use common areas? y n **Skip to question 6.5**

Other _____

6.2 How many people stay there? _____

6.3 How many rooms does it have? (not including bathrooms, halls or vestibules) _____

6.4 How old is the place? <5 years 5-10 years 11-25 years >25 years Don't know

6.5 Are there pets inside the place? y n **If no, go to 6.8**

If yes: What kind? _____

How many? _____

6.6 How many people smoke inside?

6.7 Are you aware of any mould in the place? y n

6.8 How would you rate the ventilation/air quality? 1 2 3 4 5
Very poor-----Very good

APPENDIX II

A: Interview Guide (Created by DTT project group)

1. **(Introduction of research coordinator) Please tell me a bit about yourself.**
 - What do you call home?
 - Where do you feel most at home?

2. **Could you tell me about a typical day for you before you were sick with TB?**
 - Is this different from other days of the week?
 - Where do you eat? sleep?
 - Activities in the community
 - Travel outside the community
 - Support for daily activities

3. **What kinds of things come to mind when you think of a healthy person?**
 - What does a healthy person think? Feel? Do?
 - What ways do you seek healing?
 - What gives you strength?
 - Follow up on activities mentioned

4. **What kinds of things come to mind when you think of a sick person?**
 - What does a sick person think? Feel? Do?
 - How would a sick person become well?
 - Who would help them?
 - Follow up on activities mentioned

5. **Tell me about becoming sick with TB.**
 - Where did you go?
 - How do others around you view TB?
 - Support
 - Historical vs. experiential

6. **What are some other diseases in your community that people are talking about/worried about?**
 - How do these compare to TB?
 - Has anybody talked about HIV?
 - Other STIs?

B: Rationale for Interview Tool (Created by DTT project group.

Qualitative Interview Tool

Overall Question: Why is TB Transmission Occurring?

Category	Rationale	Themes
Perceptions of Social Capital	Many factors interact to create a feeling of support and a sense of belonging among the individuals that form a community. Three indicators of social capital that have been generally agreed upon in the literature include trust (in others and institutions), civic engagement (community participation), and quality of social networks (family, workplace, recreation). It has been postulated that communities that are considered healthy and have members that are actively engaged in community activities may promote health in individuals. One study reported that social capital is highly predictive of TB at the state level (Holtgrave & Crosby, 2004).	<ul style="list-style-type: none"> • Safety • Social support
Physical and Geographical Characteristics	Some theory suggests that there are problems associated with movement/migration and TB transmission (Barnes et al., 1999; Moss et al., 2000; Norris et al., 2003). Other research identifies that risk factors associated with increased TB transmission include poor ventilation, lack of natural light, and overcrowded living conditions (Cantwell et al., 1998; Clark et al, 2002).	<ul style="list-style-type: none"> • Pattern of movement • Housing/State of repair
Characteristics of Resilience	Resilience has been studied from an individual, family, and community perspective within a variety of contexts such as substance abuse, natural or economic disasters, and critical events such as illness or war. Resilience is defined as the ability of people to ‘spring back’ in the face of adversity or the ability to resist or recover from adversity (Jacelon, 1997, p. 123). This concept may be important in understanding why some Aboriginal individuals/families get TB while others do not.	<ul style="list-style-type: none"> • Self-worth • Characteristics of transmission (May also relate to physical characteristics)
Health Care Seeking	Access to and experience with health services is a factor that influences delay in seeking treatment, compliance with treatment regimes, and completion of treatment (Klov Dahl et al., 2001). Spirituality also plays a central role in the type and order of health care seeking as well as one’s overall view of health (Beals et al., 2006; Cho, 2004; Desio et al. 2004).	<ul style="list-style-type: none"> • Access to services (May also relate to social capital) • Spirituality and health/holistic view of health (May also relate to cultural capital) • Historical and

	<p>Perceptions of disease and existence of stigma around social factors of disease may also affect the timing of health care seeking and the people through which health care is sought (Zhang et al., 2006). Early diagnosis is an essential component of TB control and is particularly important to the interruption of transmission. Understanding the factors that influence health care seeking may assist in the development of recommendations to enhance the provision of appropriate health services.</p>	<p>contemporary perceptions of TB (May also relate to cultural capital, resilience)</p> <ul style="list-style-type: none"> • HIV
Cultural Capital	<p>A number of studies highlight the fact that cultural practices or beliefs can negatively affect adherence to TB treatment or health care seeking. Another approach has been to view culture as a resource (Bourdieu, 1984). Although the term cultural capital has most often been linked to the social sciences, there is a growing body of literature identifying cultural practices and assets as having a strong role to play in the maintenance of health (Kawaja & Mowafi, 2006). In the case of TB programming, cultural capital can help identify entry points for building awareness around TB and treatment as well as encouraging knowledge exchange and discussion between patients and health care workers.</p>	<ul style="list-style-type: none"> • Spirituality and health • Community involvement in fighting TB

APPENDIX III

Moana Oh Interview Guide

What do you know/understand about TB?

What do you think causes TB?

How do you think TB infection is spread?

What problems, do you think, people face when they have TB?

How do you think TB affects a whānau ?

Tell me about when you found out that you had TB.

Do you know/recall how you knew you had TB?

What type of TB have you got/had?

How do you think you came to have TB?

What do you think caused your TB?

When did you notice changes in your health?

What have been the main problems of living with TB, for you?

How did your whānau respond to your having TB?

How has it affected your whānau ?

Have you told people outside of your whānau ? Reaction?

How has TB made you feel?

How are you feeling at the moment or how is your health now?

Can you tell me about the treatment you have had for TB?

What type of treatment have you been having?

How long?

What side-effects have the drugs had on you?

Where do you usually have your treatment?

Is that close to where you live?

How did you get to medical appointments/treatments?

Were you hospitalised? How was that?

Who are the main people involved in your treatment?

What do you think of the medical people that have cared for you?

How often do you visit them (doctors, nurses, others)

Did you consider alternative forms of treatment? (herbal, Chinese, Māori)

Did you discuss your treatment choices with people other than medical staff?

Can you tell me about how you feel/identify with being Māori ?

Your Iwi? Regular contact with your tribal grounds/marae?

Are/Have you been involved in Māori cultural activities e.g. *Kapa Haka*?

Do you speak Māori ? When do you speak Māori most often? How did you learn?

How responsive do you think health services have been to your being Māori ?

When you hospitalised did you prefer whānau to come in and care for?

Did the hospital staff accommodate this?

Traditional Māori healers/medicines

Why did you choose to use a Māori service provider?

What is your understanding of the Treaty of Waitangi?

What is your understanding of the Treaty?

What do you think the Treaty means?

Do you think the Treaty has much influence in policy or political decisions?

Have you heard of the principles of the Treaty?

Do you know what the principles mean?

Do you think Māori can influence what is happening politically in our country?

How would you describe your economic circumstances?

Age?

How many people in your immediate family?

How many people live here?

How do you get income?

Are you working?

Before you were ill, how did you earn a living?

How did you come to be on a benefit?

APPENDIX IV

Roannie Ng Shiu Interview Guide

There is not a specific interview guide for Ng Shiu's interviews with Pacific TB patients from New Zealand. Ng Shiu conducted semi-structured interviews allowing the interviewees to describe their lived experiences with TB. The interviews were designed as to encourage participants to talk about how TB has impacted their lives socially as well as allow them to speak about their beliefs surrounding TB, health and traditional medicine (Ng Shiu, 2006).