

**African Migrants and TB in Aotearoa New Zealand:
The Role of Individual, Social, Economic and
Structural Factors**

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Abstract

The post 2015 tuberculosis (TB) strategy by the World Health Organisation (WHO), “Towards TB elimination”, which is aimed at eliminating TB by 2050, has brought with it a new sense of urgency to eliminate TB in low-incidence countries. To attain these targets demands more focus and targeted interventions for the populations most at risk of TB, such as migrants. Migrants living in low incidence countries, including New Zealand (NZ), are disproportionately affected by TB and remain an important challenge to achieving TB elimination targets.

This thesis sought to contribute to the control of TB among migrants by answering the questions: what is the epidemiology of TB including that of African migrants living in NZ and; what factors contribute to the relatively high rate of TB among this group?

To answer these questions, a sequential explanatory mixed method approach, framed within a critical realist perspective, was employed in two phases. Phase I involved a descriptive epidemiological analysis of national TB surveillance data, 2010-2014. In the second phase of the study, participants were purposively sampled and interviewed one on one using a semi-structured approach. A hybrid thematic data analysis method was used in the analysis of the interview data.

The analysis from phase I showed that NZ is unlikely to achieve the TB elimination target by 2050. The findings demonstrated that between 2010-2014, Africans living in NZ had the highest cumulative incidence rate of TB (24.3 per 100,000) compared to other foreign (21.75 per 100,000) and NZ born (1.96 per 100,000). It further showed that African migrants living in NZ diagnosed with TB were more likely to be notified within the first year of arrival, commonly originated from the southern Africa region, and were commonly unemployed (20%), healthcare workers (14.1%) and students (10.6%).

The interviews with participants offered some explanation for the observed TB epidemiology. The interview data suggest that many Africans may go through difficult settlement challenges within the first few years of arrival and with that an increased risk of TB reactivating. The findings further suggest that TB may invoke a double stigma within the African community due to its link with HIV. In addition, structural factors such as the immigration NZ policy, mistrust of healthcare providers and cost contribute to delays or non-reporting of symptoms suggestive of TB.

This thesis demonstrates that TB incidence among Africans is more likely the outcome of a complex interplay between several factors including, individual, economic, social and structural. Hence, interventions aimed at TB prevention and elimination must holistically address the underlying factors, and avoid a fragmented approach that tends to emphasise the biomedical approaches.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.



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Ethics Approval

The Auckland University of Technology ethics review committee approved this study (**reference 16/128**). The study further received an out of scope letter from the NZ health and disability ethics committee (HDEC). Also, the Auckland district health board research review committee approved this study (**A+ 7254**).

Chapter One – Exploring TB determinants among African migrants: Introduction

1.0 My Journey

From the outset, I would like to relate my own experiences, as a migrant living in New Zealand (NZ), to the research topic and show how that has shaped this study. I came to the PhD journey after some years of practice as a professional health promotion officer in my home country, Ghana. I identified the need for more robust evidence for health promotion action early on in my practice. The desire to contribute to an evidence based intervention design and to take advantage of new career opportunities in research led me to apply for a PhD position at Auckland University of Technology (AUT).

The current topic evolved from my interest to understand the underlying factors that influence the health of people (the determinants of health), and, through my initial interactions with my supervisor. I have had some experience in the field of human immune deficiency virus (HIV) and tuberculosis (TB); and from practice, I knew how poverty and other structural factors influenced TB in Ghana. However, I was unaware of the extent to which these factors might influence TB in NZ. It was all new and intriguing.

The first few weeks were fun. Two months later, I had made several online applications for jobs in my field of study and expertise. I was confident that I would secure a “good” part time job in no time after arrival because I held a master’s degree in public health – health promotion from the United Kingdom (UK), which I anticipated would be highly favoured in NZ. For all my applications, however, I received nicely worded responses of rejection. I would later learn that I needed to have NZ work experience.

In the days that followed, I became desperate as I needed money for my upkeep and to remit to my family - my wife and two kids - back home. My acquaintances suggested I try fruit picking in the farms. I happily joined them to the farms as a strawberry picker for two weeks. Luckily, a PhD student friend informed me about an opportunity to teach at a tertiary education establishment and introduced me to the programme leader. I was successfully interviewed and got the job. A few weeks later, I was appointed as a teaching assistant to my PhD supervisor. I became a lot more comfortable.

A year later, I had successfully secured visas and relocated my wife and two kids to join me in Auckland. In the months that followed their arrival until now, I have come to appreciate, through my own life experiences, the real challenges faced by migrants in their new countries. The challenges are multifaceted. In my case, it spans from having to enrol my kids in school, paying for fees (tuition, stationary, uniforms), and to balance the demands of work times with school drop offs and pickups. On top of that is meeting the demands of food, transportation and weekly rent. Living in a semi-insulated building demanded more heating during winter, but the high cost meant we would heat up in the mornings and at nights before sleeping, and put on as many layers of cloths as possible during the day.

One event that brought my study into sharp focus in my own life was when my wife was admitted to hospital. Prior to this, she had been working as a care giver in a rest home. She is a registered general nurse from Ghana. To practice her profession in NZ requires that she passes an English test (IELTs) and enrol for about a six weeks' competence assessment programme (CAP). While this may be standard practice, passing the test and raising the needed tuition fee can be extremely difficult. Hence, getting a job in a rest home, no matter how difficult and less fulfilling, was a great relief for us.

About a week before her admission to hospital she had been complaining of severe pains. Her remedy during this period was a regular intake of Panadol. She took as many tablets as possible to soothe the pain and to keep her working her night shifts, while trying to catch some sleep during the day when the excruciating pain had subsided. We decided to ignore the initial symptoms, hoping it was a normal occurrence and one that would disappear after some time. Although we are both health professionals and knew the implications of our actions, we feared the cost of health care services. We knew her one-year work visa did not qualify for free healthcare services and so we did not want to visit the General Practitioner (GP). GP services in NZ are not free, and in her case, she paid NZ\$60 per consultation. Our apprehension to seek help from the health care providers was not just the cost of GP services, but the fear of possible referral to hospital level care and the other diagnostic tests, which we imagined would be too expensive for us at the time.

She was later to be admitted to hospital upon her visit to the GP, who after examining her had to call the ambulance to transport her for an emergency surgery at the hospital. Her three days stay at the hospital was a difficult one for us. We did not have any support from family as we live by ourselves, alone and far from home. Again, our network of friends were predominantly students, who were busy and could not do much. This was a stark contrast to what one would expect back home, where family and friends would voluntarily visit and offer unsolicited support.

My life in NZ as a migrant has undoubtedly informed this thesis. It has strengthened my belief that the health conditions, including TB, among migrants are not necessarily because they arrive with diseases or that they are exceptionally prone to diseases. Most migrants arrive healthier than the local population (Vang, Sigouin, Flenon, & Gagnon, 2017). Their health, I believe, deteriorates over time due to the difficult conditions of their living in the new host country.

1.1 The TB Challenge

Tuberculosis (TB), an infectious bacterial disease that can affect any part of the human body, is transmitted through the air mainly from the droplets nuclei of humans with pulmonary TB (or laryngeal TB) when they cough, sneeze or talk. TB has afflicted humanity since antiquity and has been called Phthisis, Consumption and White Plague in the past (Dormandy, 2001). These names reflected how TB was perceived throughout the ages, as the one disease that “consumed” the affected individuals leading to weight loss, weakness, pallor and deaths (Dormandy, 2001). Also, TB had catastrophic consequences on the lives of the immediate families, acquaintances and communities of the affected individuals (Dormandy, 2001).

Even today, with improvements in diagnostics and several decades after the introduction of the BCG vaccine and anti-TB drugs (perceived as the panacea to the disease), TB continues to plague many people in the world. In 2015 alone, an estimated 10.4 million people were affected and 1.8 million died from TB (1.4 million among HIV-negative people and 0.4 million among HIV-positive people), and yet about four million more people were living with undiagnosed or unnotified TB (WHO, 2016). TB is curable, but caused more deaths than HIV/AIDS and was the leading cause of death from infectious diseases in 2015 (WHO, 2016).

Globally, TB control efforts have been inconsistent. They (control efforts) gain momentum during periods of a sudden rise in TB incidence and dwindle when the rates decline (Reichman, 1991). This phenomenon, where TB programmes and funding decline with the downward trend of incidence to create a favourable condition for resurgence has been famously referred to as “the U-shaped curve of concern” (Reichman, 1991). For instance, TB disappeared from the list of global health priorities from the 1960s with the decline in incidence only to return in the mid-1980s and 1990s following the HIV/ AIDS pandemic and resurgence of anti-TB drug resistance (Reichman, 1991).

At present, TB affects every region of the world, although a high level of disparity between and within countries exists. Within countries, people on the lower level of the socio-economic spectrum are the most affected while those on the higher level are the least affected (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). This is similar between countries, as low income countries report more cases than high income countries (Lönnroth et al., 2009). Thus, the inequalities in TB burden follows the existing socio-economic gradient that runs from the bottom to the top of the socio-economic spectrum.

In many high-income countries including NZ, the search for the ‘magic bullet’ to eliminate TB has intensified following the introduction of the post 2015 TB strategy by the WHO. The new WHO strategy, “Towards TB elimination”, is aimed at eliminating TB by 2050 (Lönnroth et al., 2015). In these new targets, low incidence countries, defined as countries reporting less than 100 cases per 1,000,000 population (WHO, 2015b) are required to achieve pre-elimination (defined as less than 10 TB cases, all forms, per 1,000,000 population) by 2035 and subsequent elimination (defined as less than 1 TB case, all forms, per 1,000,000 population) by 2050.

One enduring threat to TB elimination in these low incidence countries including NZ is migration; foreign born persons living in these countries contribute the highest proportion of all annually notified TB cases. Globally, an estimated one billion people are migrants with the numbers projected to rise in the subsequent years (Dhavan, Dias, Creswell, & Weil, 2017). The frequent occurrence of emergencies including conflicts, famine, economic instability and/or natural disasters has led to a sharp increase in the number of migrants to Western countries, especially Europe. This influx has been met with some strong anti-migrant sentiments in many host countries (Potter, 2017). Previous studies in NZ have noted that such anti-migrant sentiments strengthen the feeling of “otherness” and marginalisation that migrants experience in all aspects of their life

including employment, education, housing, health and other social services (Lawrence, 2007; Littleton, Park, Thornley, Anderson, & Lawrence, 2008).

Much like the previous public health action on TB control that prioritised biomedical approaches, the reinvigorated drive to end TB in low incidence countries has seen an overemphasis on improvement in available diagnostic tools. Particularly, around pre-arrival and post-arrival screening and treatment of latent TB infection and disease. For instance, the Ministry of Health (2010) guidelines for TB control in NZ, currently under review, is somewhat biased towards the biomedical approach. It focuses on the biological factors of the disease – its prevention, treatment and diagnosis – rather than addressing the underlying and wider determinants that contribute to TB incidence. In most cases, addressing the underlying factors is perceived as complementary rather than the fulcrum around which efforts to eliminate TB should revolve (Hargreaves et al., 2011; Wallace, 2001). While improvement in the existing tests are necessary and would contribute to minimising TB reactivation among high risk groups (Zenner, Loutet, Harris, Wilson, & Ormerod, 2017), there are debates about the accuracy of the existing screening tests to predict progression from latent TB infection to active TB (Diel, Loddenkemper, & Nienhaus, 2012; Rangaka et al., 2012; Zenner et al., 2017). This uncertainty about the predictability of the test and the potential for reinfection even after treatment, strengthens the argument for a shift in focus from the narrow individual centred interventions to complex dynamic interventions that holistically address the underlying influencers of TB, especially among high risk groups including migrants.

1.2 Rationale and Significance of Study

NZ is required to eliminate TB by 2050 like other low incidence countries. Given the new targets, NZ needs to achieve an annual rate of decline of about 11% over the set period, a rate that is more than three times the decline observed between 2000-2012

(3.8%) (Lönnroth et al., 2015). To achieve these targets and be counted among the countries to have eliminated TB, arguably, would require more targeted interventions for most at risk groups including migrants. Importantly, any intervention aimed at reducing TB incidence among migrants needs to be guided by epidemiological analysis of trends of TB among such groups to establish the TB distribution pattern by sex, age, ethnicity and location, among others. There is also the need to assess how personal and other social, economic, and structural factors influence TB acquisition, transmission, prompt diagnosis and treatment. Understanding the complex interactions between these mechanisms is necessary in order to develop effective public health interventions.

Despite the growing global concern to address the existing inequities in the TB burden, especially among migrant communities in low incidence countries, there has been no study describing the epidemiology of TB among Africans in NZ. A previous study focused only on the Somali refugee community in NZ (Lawrence, 2007). With TB rates still relatively high among African migrants, this study will significantly contribute to addressing the gap and will be central to the development of future interventions targeted at African migrants.

On a broader level, it is expected that this study will contribute to the body of knowledge on TB among migrants living in Western countries, the theoretical understanding of migrant health and specifically to that of African migrants living in NZ. The study offers an opportunity to understand the challenges faced by the African migrant population, and aims at influencing public health policy and practice through recommendations from the perspectives of the community. In essence, this research intends to give a voice to the marginalised in society, one of the core principles of public health research and practice and in line with the Ministry of Health priorities for control of communicable diseases. It would specifically contribute to the WHO's Priority Action

Three for the elimination of TB, which is aimed at addressing TB needs of migrants (WHO, 2014).

1.3 The Current Study

In this thesis, I have contextualised the determinants of TB among persons born in sub-Saharan Africa living in NZ (here after referred to as African migrants) in terms of the complex interactions between six main factors. The first relates to the country of origin factors including TB burden and experiences of migrants before and/or during migration. These factors may interact, independent of our knowledge of them, to influence the exposure of migrants to latent TB infection before arrival. The other five are the host country factors and include the settlement/integration, individual, social, economic, and structural factors. The host country factors influence the reactivation of latent TB infection to TB disease from previously acquired or recently acquired TB infection. Whilst the available data suggest that the burden of TB among African migrants in NZ is relatively high, I argue that being an African, in itself, does not put one at risk of TB. However, the extent of interaction between the five factors would have a profound influence on whether an African migrant might acquire or develop TB.

1.4 Aim and Research Questions

The aim of this study is to understand the epidemiology of TB among African migrants living in NZ. The study answers two research questions: what is the epidemiology of TB including that of African migrants living in New Zealand; and what factors contribute to the relatively high rate of TB among this group?

1.5 What Factors Influence the Decline of TB?

The rapid decline in TB mortality from the mid nineteenth to the twentieth century in the industrialised countries offer lessons for the current and future interventions in achieving the bold global TB elimination targets. However, opinion on the relative contribution of the major factors to the decline in these periods is still debated in the literature. Three main reasons have been offered: improvement in nutrition (McKeown & Record, 1962; McKeown, Record, & Turner, 1975); natural selection (Davies, Tocque, Bellis, Rimmington, & Davies, 1999); and public health action through deliberate policies and changes in the social structure (Fairchild & Oppenheimer, 1998; Farmer, 1997; Grange, Gandy, Farmer, & Zumla, 2001; Lienhardt, 2001). These factors and associated debates are discussed below.

McKeown has argued that the steady decline of TB mortality in the nineteenth century was influenced by the progressive improvements in living standards (McKeown & Record, 1962). While ruling out the other possible explanations for the decline, McKeown and Record were convinced that the possibility of natural selection and medical interventions (preventive or curative therapy) did not contribute to the decline of TB mortality in the nineteenth century. They believed that the available medical treatment at the time were less effective to influence the decline. For them, the most plausible reason was the changes in the environmental factors. They observed that ‘inadequate diet’ was largely the reason for the rise in mortality due to TB during the two world wars, and further explained that, while nutrition improved after the wars, other factors including housing did not. For instance there was a slight decrease from 5.6 persons per house in 1801 to 5.3 persons per house in 1871 (McKeown & Record, 1962). They concluded that “improvements in diet was probably the main cause of the decline of mortality from tuberculosis during the nineteenth century” (McKeown & Record, 1962, pg. 116). While acknowledging that the introduction of chemotherapy had accentuated the reduction in

mortality in the twentieth century, McKeown and his colleagues were still convinced that the main factor influencing the decline of TB mortality was improved nutrition (McKeown et al., 1975).

The series of writings by McKeown in what has become known as the “McKeown thesis” further intensified the debate with other scholars critiquing his conclusions and expounding their own reasons for the decline. For instance, Davies and colleagues suggested that the reduction in mortality was due to natural selection of a population that was more resistant to TB (Davies et al., 1999). They argued that acquired immunity against TB was a more plausible explanation because mortality from TB declined steadily from the mid nineteenth to the early twentieth centuries whereas reduction in infant mortality, an indication of social improvement, was slow (less than twice the TB mortality decline). This pattern, they further argued, was similar to the other infectious diseases such as cholera and dysentery, which did not show any statistically significant decline, suggesting that improvement in social deprivation alone was not enough to explain the steady downward trend of TB mortality.

Other scholars have argued that the downward trend in TB in the industrialised countries could not be the result of improved nutrition and living standards or natural selection alone (Fairchild & Oppenheimer, 1998; Farmer, 1997; Lienhardt, 2001). They argue that accepting the McKeown thesis will mean that no innovation would be required in TB control efforts by proceeding on the assumption that addressing poverty and the other root causes of poverty could result in TB reduction and successful elimination. They believe that the reason for the decline was multifaceted including deliberate public health action through advocacy and policies that addressed occupational hazards, overcrowding, housing, poor ventilation and improved sanitation. For instance, a radical change in political response to TB due to its resurgence and the public fear that TB could widely spread if left untreated, culminated in increased funding for TB control from the US

senate (Fairchild & Oppenheimer, 1998). The scholars further argue that, although TB is biological in nature, the best approach to understanding and controlling it should be through a ‘socio-medical’ approach because the disease is produced by social forces that transcend the health system (Farmer, 1997). Considerations to understanding the mechanisms of the social, economic and structural factors are as important as that of how the bacilli causes TB in the host because the incidence of TB is inextricably linked to social, economic and structural factors (Farmer, 1997; Lienhardt, 2001).

What is apparent from the existing debate is the notion that mono-causal explanation for the decline in TB mortality, whether biological or improvements in living standards alone may be flawed and unsubstantiated by the evidence. The overemphasis of one over the other, for example, the emphasis on institutional segregation, hygiene education, occupational hazards improvements, pasteurisation, and TB eradication in cattle, were largely because these interventions were cost effective, politically realistic and could easily be expanded to reach a large majority of the population (Fairchild & Oppenheimer, 1998). Conversely, issues of poverty and other root causes were complex, difficult and required huge investments by governments to confront them, which made them less realistic politically (Fairchild & Oppenheimer, 1998).

Whilst there is the need to eradicate poverty and improve the living conditions of the many poor who suffer from TB, it is equally necessary to develop creative, innovative and more effective TB elimination strategies (Lonnroth et al., 2010). This thesis proceeds on the notion that the incidence of TB is not an outcome of a simple linear interaction between the bacilli and the host. Rather, it embraces the complex dynamic interactions existing between several mechanisms at different levels and proposes an ecological framework (model) to explain these within the context of the lived experiences of African migrants in NZ.

1.6 Thesis Overview

I have organised the remainder of this thesis into seven chapters. In **Chapter Two** I establish the context for the study by providing the reader an overview of the clinical understanding of TB and a background of TB epidemiology in the African region in relation to a brief history and epidemiology of TB in NZ. In **Chapter Three** I critically review the literature to understand what is currently known about the determinants of TB among African migrants living in Western countries and to set the scene for the subsequent chapters. I discuss (**Chapter Four**) the conceptual framework guiding the study, the philosophical underpinnings and the mixed method approach used in this study, and further justify the selection of these over the possible choices available. I present the findings from the epidemiological analysis of national TB surveillance data from 2010 to 2014 (phase I study) in **Chapter Five** and the results from the semi-structured interviews with nine participants (phase II study) in **Chapter Six**. In **Chapter Seven** I discuss the findings from both phase I and II together concurrently (point of interface) and provide the reader with an understanding of how the findings from each phase complements each other in explaining the TB epidemiology among African migrants in NZ in relation to what is already known and/or to theory. I conclude in **Chapter Eight** by presenting the implications of the study findings, and recommendations for practice, policy and research, guided by the novel African Hut Model developed from this study.

Chapter Two – Understanding TB in Context: Sub-Saharan Africa and NZ

2.0 Introduction

Early diagnosis and initiation of treatment is the mainstay of TB control. However, TB is often under recognised and goes undetected – a persistent threat to many. George W. Comstock famously said, “TB anywhere is TB everywhere”. The aim of this chapter is therefore to provide an overview of the disease, offer a description of the epidemiology of TB in the Africa region and lay the foundation to draw out the key factors that can influence TB occurrence in NZ. For the reader to appreciate how TB occurs and the factors that influence its incidence, the clinical understanding of TB must be laid out in sufficient detail. The chapter begins with the presentation of the clinical understanding of the disease, the causative agent, transmission, types of TB and clinical presentation. Further, a brief history of TB in NZ is presented followed by a description of the epidemiology of TB in sub-Saharan Africa including the determinants of the disease.

2.1 Tuberculosis

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis* complex (Ait-Khaled & Enarson, 2003). TB can affect any organ in the human body (Ait-Khaled & Enarson, 2003). In cases where it affects the lungs, it is known as pulmonary TB, which is the main source of TB infection from person to person and the most common form of TB globally and in New Zealand (Ait-Khaled & Enarson, 2003; Ministry of Health, 2010). When it affects any part of the human body apart from the lungs, it is known as extra-pulmonary TB (Ait-Khaled & Enarson, 2003). In cases of children and

persons with compromised or suppressed immunity such in HIV patients, it can affect all parts of the body and is known as miliary TB (Grange, 2007)

2.1.1 The Mycobacterium

Mycobacterium tuberculosis complex, also known as tubercle bacilli, refers to a group of mycobacteria that are related genetically and are variants of one species (Grange, 2007). They all cause TB in man and some mammals. The principal agent that causes most TB in human is the *Mycobacterium tuberculosis* (Grange, 2007). Other members of the complex are *Mycobacterium bovis*, which causes TB in cattle and rarely is transmitted to man through unpasteurized milk; and *Mycobacterium africanum* (Type 1 & Type 2), rare but found in parts of West and East Africa (Ait-Khaled & Enarson, 2003; Jacqueline, Coberly, & Chaisson, 2007).

There are several other mycobacteria species, which are opportunistic and cause infections in people, especially among those with HIV. Notable is the *Mycobacterium avium* complex isolated from soil, water and environment, which causes illness that is similar to TB in people living with HIV (Jacqueline et al., 2007).

The tubercle bacilli are aerobic, growing well in oxygen rich areas in the human body (Ait-Khaled & Enarson, 2003; Rockwood, 2007). They have a slow growth rate taking about 20 hours to replicate and can survive for long hours in the dark and enclosed spaces (Ait-Khaled & Enarson, 2003). The bacilli grow best at temperatures of 35 to 37°C but do not grow at $\leq 25^{\circ}\text{C}$ or at $\geq 41^{\circ}\text{C}$ (Grange, 2007). They are heat sensitive and are destroyed when exposed to direct sunlight or when subjected to heat such as pasteurization (Ait-Khaled & Enarson, 2003; Grange, 2007).

2.1.2 Transmission

The primary mode of transmission of TB is air-borne through the respiratory tract. Transmission of tubercle bacilli can also occur through: mucous membranes in the genitourinary tract, the gut and conjunctiva; or breaks or abrasions in the skin (Jacqueline et al., 2007). This mode of transmission leads to localized infections at the site of entry of bacilli and can lead to infections in other body organs as it spreads through the blood or lymphatic system (Jacqueline et al., 2007). This mode is relatively rare particularly in low incidence countries (Grange, 2007; Jacqueline et al., 2007).

People with pulmonary TB serve as the main source of infection (Jacqueline et al., 2007). When infected people talk, laugh, sing, and especially when they cough or sneeze, they release and discharge small sputum particles containing droplets nuclei into the atmosphere (Jacqueline et al., 2007; Ait-Khaled & Enarson, 2003). Once in open air the liquid portion dries up leaving the droplet nuclei containing infectious mycobacteria, which is light and can remain suspended in air for several hours in an enclosed and dark space (Ait-Khaled & Enarson, 2003). These floating nuclei serve as a source of infection for uninfected individuals when they inhale them.

In an uninfected person, the risk of infection depends on exposure to the bacilli, the dose or virulence of bacilli and the period or length of exposure to bacilli (Jacqueline et al., 2007). Hence, the closer and more continuous the contact an uninfected individual has with an individual with infectious TB, the higher the risk of infection (Morrison, Pai, & Hopewell, 2008). Other factors that increase the likelihood of healthy individuals being exposed to infected droplets such as poor ventilation and overcrowding increases the risk of infection acquisition (Jacqueline et al., 2007). Of concern to epidemiology of TB are the major factors that determine the chances of healthy individuals getting exposed to the bacilli, which depends on incidence of infectious individuals living in a community, the

length of their infectiousness and type of interaction they have with susceptible healthy individuals during the period that they remain infectious (Rieder, 1999).

2.1.4 How TB Develops

When a susceptible individual inhale the bacilli, they travel to the alveoli of the lungs. There, the body's defence mechanism responds to it (Grange, 2007). For some individuals, the infection rapidly progresses to disease and it is called primary pulmonary TB. Primary pulmonary TB disease occurs when an individual who has never been exposed to the bacilli develops the disease within weeks or months upon exposure to the bacilli (Crofton, Horne, & Miller, 1999). This is common for children below three years and older adults, whose immune system might be less developed or compromised due to the natural processes of ageing, respectively (Jacqueline et al., 2007). For most individuals with competent immune response systems, however, the bacilli will be completely eradicated and they will show no signs and symptoms (Jacqueline et al., 2007). For others, the body's defence mechanism contains the bacilli, slowing down its growth and multiplication, making it dormant (Crofton et al., 1999; Russell, 2007). This is termed latent TB infection. In such cases, the persons exposed do not show signs and symptoms of the disease. They would travel from their countries of origin into their new host country with the bacilli, as chest x-rays (the offshore immigration screening test) for such persons would be typically normal. Such persons can be detected when tested using a tuberculin skin test or interferon-gamma release assays (Brandli, 1998).

Among individuals infected with latent TB infection (LTBI), the containment of the bacilli may fail over time due to a weakening of the body's defence mechanisms, usually because of old age, malnutrition, poor health, and other concurrent diseases such as HIV, which allow the dormant bacilli to grow and multiply, causing the disease. This

process is known as reactivation of latent TB infection (Russell, 2007; Crofton et al., 1999), and leads to post primary or reactivation pulmonary TB disease in about 5-10% of previously exposed individuals (Brandli, 1998). Reactivation of previously acquired latent TB, most likely from migrants' countries of origin due to the high burden of TB, has been suggested as the most likely contributor to TB disease among migrants in high income countries (Dhavan et al., 2017; Lonnroth et al., 2017).

2.1.5. Extra-pulmonary TB

This type of TB affects other human organs apart from the lungs. Due to its early spread through the blood or lymphatic system extra-pulmonary TB may be detected in about 20% of infected individuals (Brandli, 1998). For most insidious extra-pulmonary cases, however, it may be difficult to detect, leading to delays in diagnosis and treatment (Brandli, 1998). Some common types of extra-pulmonary TB include:

Lymph Node TB: this is the most common type of extra-pulmonary TB and affects any group of lymph node leading to about 50% of all extra-pulmonary cases (Brandli, 1998; Ministry of Health, 2010). It mostly affects lymph nodes in the neck, but lymph nodes in the groin and armpits may also be affected (Crofton et al., 1999). These swollen nodes are normally painless and grow slowly (Crofton et al., 1999). Children infected with HIV/AIDS may have general swollen lymph nodes of the body (Crofton et al., 1999).

Pleural TB: this type of TB occurs more in adults than in children and is the second commonest type of extra-pulmonary TB, causing about 14.5% of all extra-pulmonary TB cases in NZ (Ait-Khaled & Enarson, 2003; Institute of Environmental Science and Research Ltd (ESR), 2015; Ministry of Health, 2010).

Skeletal TB: this occurs when the bacilli spread to affect any bone or joint (Crofton et al., 1999). It is more common in younger children than in adults in highly

endemic countries but more common in older people in high income countries (Ministry of Health, 2010). TB can affect any bone or joint, however, the ones that bear more weight such as the spine, hip, knee, and foot bones are commonly affected (Crofton et al., 1999). The most common form of skeletal TB is TB that affects the spinal vertebrae also known as Pott's disease (Ministry of Health, 2010; Ait-Khaled & Enarson, 2003). It is difficult to diagnose this type of TB leading to delays in treatment (Crofton et al., 1999). Common symptoms are pain in the neck, shoulders, back, knee or hip.

Abdominal TB: TB bacilli reach the gastrointestinal tract (GI Tract) when: infected persons ingest sputum containing the bacilli; through the blood or lymphatic system; from adjacent organs, which are infected; and, rarely, through the ingestion of infected cow's milk (Sharma & Bhatia, 2004). In children, the bacilli may reach the GI tract through food or fingers from an infected adult who releases large numbers of bacilli through coughing and does not practice proper hand and environmental hygiene (Crofton et al., 1999). This disease may mimic other diseases making it difficult to be diagnosed and sometimes missed (Sharma & Bhatia, 2004; Addison, 1983). The most common symptom is abdominal pain and weight loss, which is similar to other diseases (Sharma & Bhatia, 2004; Addison, 1983). Young people and children are the most affected by this type of TB (Sharma & Bhatia, 2004; Addison, 1983).

Genitourinary TB: this type of TB develops later, usually after five to 15 years of primary infection, which makes it a rare occurrence in children (Crofton et al., 1999; Fanning, 1999). It occurs when bacilli are spread through the blood from the primary infection sites to the kidney, the female genital tract (affecting the endometrium, ovary or fallopian tubes), or the male genital tract (affecting the prostate, epididymis and or seminal vesicles) (Crofton et al., 1999). It is silent, has no classical symptoms and can lead to infertility, lower abdominal pain or menstrual problems, which normally leads people to seek medical help (Ministry of Health, 2010; Crofton et al., 1999). Some

symptoms of genitourinary TB include painful urination, blood in urine, painful loins, or change in urine frequency.

Neurological TB: TB can affect any part of the central nervous system. It begins when the bacilli travel through the blood stream to reach the nervous system (Crofton et al., 1999). The most common form of TB affecting the nervous system is TB meningitis, which occurs mostly in children under five years and in immunosuppressed adults (Ministry of Health, 2010). The symptoms of TB meningitis are similar to that of other bacterial meningitis, which sometimes leads to a wrong diagnosis and delayed treatment (Ministry of Health, 2010). The disease develops slowly and requires a high level of suspicion to diagnose and treat early (Fanning, 1999). Delay in diagnosis and start of treatment leads to increased damage to the brain and risk of mortality (Fanning, 1999; Ministry of Health, 2010; Crofton et al., 1999). Some of the symptoms of neurological TB include headaches, vomiting, stiff neck, loss of speech, or fits.

Cardiovascular TB: a rare TB type in most parts of the world seen relatively commonly in places with high HIV infection rates (Ministry of Health, 2010; Crofton et al., 1999). It occurs when bacilli from primary infection sites in other parts of the body are transported through the blood stream to the pericardium or when a lymph node ruptures into the pericardium (Crofton et al., 1999). Patients show signs of breathlessness, oedema, low blood pressure and rapid pulse (Ministry of Health, 2010). Other symptoms are fever, sharp pain, low blood pressure and high pulse rate.

Other types of TB: the other parts of the human body are rarely affected by TB through spread of the bacilli in the bloodstream (Fanning, 1999). TB can affect larynx, pharynx, mouth, epiglottis, ear, eye, skin and adrenal glands among others (Fanning, 1999; Crofton et al., 1999; Ministry of Health, 2010).

2.1.6 Clinical Manifestation

In most cases the signs and symptoms of TB do not show until the disease is advanced. To suspect a person of TB disease, clinicians look for the cardinal symptoms. These include a cough usually lasting for more than three weeks, fever or sweating especially in the late afternoon or in the night, weight loss, tiredness, blood in the sputum or blood spitting and chest pain (Crofton et al., 1999; Ministry of Health, 2010). Identifying people with TB mostly occurs when they present themselves to healthcare facilities for treatment and for ailments. High suspicion on the part of clinicians is the most common way of identifying TB cases in most countries, which leads to some cases of TB being missed every year (Crofton et al., 1999; Brandli, 1998). In 2015 alone, an estimated 4.3million people with TB were missed globally, which partly reflects under diagnosis, as some persons with symptoms suggestive of TB do not report to healthcare providers for help (WHO, 2016).

In pulmonary TB, the cough produces sputum (productive) though it is dry initially, but children normally do not produce sputum (Crofton et al., 1999). Other symptoms include localised wheezing and breathlessness (Gough & Kaufman, 2011). In addition to general symptoms of TB, extra-pulmonary TB may lead to symptoms associated with the organ or part of the body infected (see section **2.1.5**).

2.1.7 Diagnosis of TB

As stated earlier, a major focus of TB control is to identify people with infectious TB disease and treat as early as possible to avoid transmission (Harries, Maher, & Graham, 2004). In that regard, it is recommended that all persons with symptoms suggestive of TB should be assessed through laboratory procedures to identify (isolate) mycobacteria or by using TB antigens to assess their immunologic response (American

Thoracic Society and the Centers for Disease Control and Prevention, 2000; Harries et al., 2004).

The most widely used test to identify latent TB infections is the Tuberculin Skin Test (TST), which involves injecting purified protein derivative (PPD) obtained from *M. tuberculosis* cultures beneath the surface of the skin, preferably the forearm area (ATS/CDC, 2000). In cases where a person has a latent TB infection, an induration is observed at the site of injection. The diameter of the induration is measured between 48 to 72 hours after injection (Ministry of Health, 2010). Reading test results must be done with caution. This test can yield false negative results among malnourished, immunosuppressed, or people with other illnesses (ATS/CDC, 2000). Live-attenuated vaccines such as polio, yellow fever, measles, mumps and rubella may also lead to false negative results (ATS/CDC, 2000). Infection from other mycobacteria and BCG vaccination may also induce false positive results (ATS/CDC, 2000).

Another test that is used to detect latent TB infection is the Interferon-gamma release assays (IGRA). In New Zealand, QuantiFERON-TB Gold In-tube assay, a type of IGRA is used to test for TB infection (Ministry of Health, 2010). The principle of the test is that, for individuals infected with TB, their blood contains cells that, when exposed to TB antigens in a test tube, will produce interferon-gamma (Jacqueline et al., 2007). The test seeks to eliminate errors in the tuberculin skin test and to eliminate the need for patients to return to healthcare facilities for interpretation of the test (Jacqueline et al., 2007).

Diagnosis of active TB disease involves assessment of clinical presentation, epidemiological risk and clinical investigation such as sputum smear microscopy, culture test, chest x-rays, and nucleic acid amplification test (Jacqueline et al., 2007). Chest X-rays are commonly used as a screening test to identify changes, which may suggest a case

of TB (Ministry of Health, 2010). This may require further assessment to confirm a TB case.

Sputum smear microscopy is the most common method for identifying TB bacilli especially in resource poor settings (Jacqueline et al., 2007). It is easy, relatively cheap, simple, has high specificity and gives an indication of the number of bacilli a patient may transmit (Singhal & Myneedu, 2015).

A much more sensitive test is the culture test, which is used to grow the mycobacteria from a clinical specimen and to also assess the drug susceptibility of the organism (Harries et al., 2004; ATS/CDC, 2000). A culture test may be used for the diagnosis of extra-pulmonary TB by taking clinical samples from the appropriate site of infection and growing it on an appropriate culture medium (ATS/CDC, 2000).

Nucleic acid amplification tests are fast and are used mainly to confirm smear positive results (ATS/CDC, 2000). They are considered an improvement over other tests in detecting bacilli directly in a specimen (Jaqueline et al., 2007). This test is approved for use in New Zealand and is done in some hospitals in the country (Ministry of Health, 2010).

Contrary to what pertains in developed countries, in most developing nations where TB is still endemic, diagnosis still relies heavily on clinical symptoms and sputum smear microscopy (Harries, Maher, & Graham, 2004).

2.1.8 Treatment of TB

Treatment is one of the most important steps in TB control (Rieder, 2002). Largely because in TB control the focus is to reduce transmission of new cases. Promptly identifying people infected with TB and TB transmitters is not enough to reduce the transmission of the disease. Treatment with anti-TB drugs is the sure way of making TB

transmitters non-infectious (Rieder, 2002). The primary aims of treatment therefore are to: cure patients thereby reducing chances of transmission to uninfected individuals; reduce the clinical development of the disease and harm on affected persons; and prevent deaths due to TB (Harries et al., 2004).

Current treatment regimens have two phases. An initial phase, also known as “the intensive phase”, uses more drugs and is followed by a “continuation phase”, which uses fewer drugs (Arnadottir, 2009). According to the guideline for TB control in New Zealand (2010), adults with active TB disease are to be treated using a standard six months’ regimen with isoniazid, rifampicin, ethambutol, and pyrazinamide for the first two months in the intensive phase followed by isoniazid and rifampicin for four months in the continuation phase.

The guideline recommends that persons with TB be assigned to one of three levels of supervision, self-medication, close supervision or directly observed therapy (DOT) (Ministry of Health, 2010). Persons assigned to DOT receive their medication daily or thrice weekly (intermittent DOT) from public health nurses or other health professionals and are observed by these professionals to swallow the medicines. Persons on DOT are unable or unwilling to self-medicate, have relapsed, are drug resistant, have extensive disease, co-morbidities or are highly infectious (Ministry of Health, 2010). Those assigned to close supervision take their medicines daily and are visited by the public health nurses at least weekly. They are less at risk of non-adherence to treatment compared to persons on DOT. People with TB assigned to the third level, self-medication, take their medications daily and are visited at least within 28 days. Of the three levels, people under self-medication are the least likely to not adhere to treatment (Ministry of Health, 2010).

Treatment of active TB has evolved over the last six decades; from 12 to 18 months in early 1950s, to nine months in 1970s and down to six months from 1982, which is still the current duration for treatment (Arnadottir, 2009). A major issue spanning all these years since the development of chemotherapy has been the duration for treatment leading to challenges of treatment adherence and drug resistance (Arnadottir, 2009; Caminero, 2013). Treatment adherence is one of the themes of this thesis and will be critically reviewed in subsequent chapters.

2.2 Tuberculosis in NZ: A Brief History

New Zealand, located in the South Pacific, is the largest island in the region of Polynesia. Geographically, it is remote and one of the most isolated temperate islands. It is believed that, before the first settlers arrived in New Zealand, there were only a few infectious disease causing microorganisms that existed on the island (Crump, Murdoch, & Baker, 2001). The major reason for the relatively few infectious microorganisms has been attributed to NZ's environment, which was not conducive for most infectious microorganisms; and the native fauna, which did not at the time include known intermediate hosts for most of the human infectious microorganisms (Crump et al., 2001). This meant the incidence of infectious diseases among the first settlers, the Māori, was low and explains the reasonably good health enjoyed by the Māori as was reflected in the strong physique, healing and good teeth (Miles, 1997; Pool, 2011).

The arrival of Europeans and the colonization of New Zealand by Britain in the 1790s, led to more migrants entering with infectious diseases, which were endemic in Europe at the time (Crump et al., 2001; Miles, 1997). Infectious diseases like TB, which previously were not known among Māori, occurred among them after European arrival and had a negative impact on Māori (Crump et al., 2001; Miles, 1997). Māori life expectancy at the time of European exploration and the visit of Captain Cook to New

Zealand between 1769 and 1777 was high (about 30 years); comparable to those living in privileged societies of the 18th century and higher than that of Britain (Pool, 2011). Evidence suggests that life expectancy of Māori began declining after the arrival of Europeans, from more than 30 years at birth to as low as 25 years for men and 23 years for women (Pool, 2011). The lack of immunity to these infectious diseases including TB had a terrible impact on Māori. It has been estimated that Māori population had declined by about 60% in the 1890s, from about 100,000 in 1769 to about 42,000 in 1896 (Pool, 2011). The spread of introduced infectious diseases, especially TB, was severe as Māori, having been reduced to poverty through the selling and confiscation of their lands, had to live on poor diets and in unhygienic and overcrowded conditions (Pool, 2011).

In the 1800s TB was believed to be caused by bad air, thus TB patients were encouraged to move to mild climates, mountainous or seaside areas for fresh air and rest to enable the body to recuperate (Dormandy, 2001). In the mid nineteenth century, as Linda Bryder argues, there was seeming competition with Australian colonies to attract British immigrants and capital (Bryder, 1996). New Zealand took advantage of its mild temperate climatic conditions to attract migrants and actively campaigned to attract them by projecting New Zealand as having therapeutic climatic conditions (Bryder, 1996). As more European migrants with TB arrived with the hope of getting cured, TB cases among migrant population (who previously did not have TB) increased through person to person transmission. TB deaths in migrants correspondingly increased, especially during the first year of arrival (Bryder, 1996).

In its efforts to fight TB, NZ declared pulmonary TB a notifiable disease in 1901 before England and some other Western countries (Bryder, 1996). In 1903, the NZ government, following the discovery of TB as an infectious disease in 1882, declared TB as a dangerous contagious disease and introduced legislation to restrict entry of individuals who had TB (Bryder, 1996).

The treatment of TB with effective anti-TB drugs began in 1946 with the introduction of streptomycin and led to an immediate reduction in mortality and improved patients' outcomes (Mitchison & Davies, 2012). The gains were short-lived due to the emergence of resistance to streptomycin. To address this challenge, streptomycin was combined with para-amino salicylic acid, which effectively minimized the development of resistance (Mitchison & Davies, 2012). The introduction of Isoniazid in 1952 further strengthened the options for the treatment of TB and, based on previous experience, was combined with streptomycin or para-amino salicylic acid or given alone. The observation that the bacilli developed resistance to one of the drugs informed the combination of the drugs in a multidrug therapy after John Crofton (1959) classic study. The major challenge at the time was the length of treatment, which lasted 12 months in a hospital setting, the cost of drugs, and hospital stay. In 1960, chemotherapy was evaluated in domiciliary settings under supervision, later to inform the directly observed therapy (DOTs) programme of WHO (Mitchison & Davies, 2012).

As noted, treatment of active TB has evolved over the last six decades, from 12 to 18 months in early 1950s to nine months in 1970s and down to six months from 1982, which is still the current duration of treatment (Arnadottir, 2009). Of concern, as stated earlier, is the time span for treatment, which may create challenges with treatment adherence and drug resistance (Arnadottir, 2009; Caminero, 2013). The development of resistance to anti-TB drugs has been observed from the introduction and widespread use of the first drugs and has extended to all other drugs (Caminero, 2013). Resistance to anti-TB drugs has been shown to consistently originate from misuse of the drugs and has been described as 'man-made' (Mitchison, 1998). Non-adherence to appropriate treatment regimen, such as irregular taking of drugs, taking lower than the recommended dosage or breaks in taking drugs has been shown to result in drug resistance (Crofton et al., 1999;

Mitchison, 1998). A person may develop primary resistance however, when he or she is infected by a patient who has resistant TB bacilli (Crofton et al., 1999)

Compulsory notification of all forms of TB was introduced in 1940 (MOH, 2010). TB incidence, like in other developed nations, saw a decline from the late 1920s to the early 30s (Das et al., 2006). During the period of the Second World War the decline in incidence reversed and peaked in 1943 with 2600 cases representing a rate of 142 per 100,000 (MOH, 2010). Some reasons offered for the sharp rise in TB incidence and mortality in most countries affected by the war include: the breakdown in sanatoria, disruption of healthcare, and subsequent discharge of occupants to their homes; poor hygiene conditions; overcrowding; and severe shortages in food supplies, all of which contributed to peoples' vulnerability to TB (Daniels, 1949). The incidence of TB declined after the World War II period amidst some peaks in the late 1980s and between 1995 and 2004. The highest rate, 12 per 100,000 population, during this period was recorded in 1999 (MOH, 2010). The reasons assigned to the reversed trend in decline were the HIV/AIDS pandemic, multi-drug resistance and migration of people from high incidence countries to developed countries (Das et al., 2006). In New Zealand, the key contributing factor to the rise in incidence observed from 1995 to 2004 was migration of people from high endemic countries (Das et al., 2006).

A change in the migration policy from favouring the traditional source countries (UK, Australia and North American countries) to one based on selection of relevant characteristics through enactment of the new Immigration Act in 1987 and subsequent introduction of the "Point System" in 1991 resulted in high inflows from diverse countries (Phillips, 2013). Between 1991 and 2006 there were significant increases in migration from Asia: mostly from China and Hong Kong (together about 85,000 migrants); North-East Asia (about 40,000) mostly from Korea, Japan and Philippines; and South Asia from India and Sri Lanka. The Asian population made up about 9.2% of total NZ population

by 2006 (Phillips, 2013). Migration from Africa within this period was largely from North Africa and the Middle East (Iraq, Iran and Somalia), mostly refugees and by 2006 were over 16,000. Although the numbers of arrivals from the UK dropped, persons of other European ethnicities arrived by 2006 – 40,000 European South Africans, 11,000 Germans, 18,000 Americans, 2,500 French and about 5,000 Russians (Phillips, 2013). The migration pattern during this period confirms the finding by Das and colleagues that the countries contributing the most number of migrants were high TB incidence countries.

At the end of 2004, NZ introduced mandatory chest X-rays to screen migrants intending to stay for six to 12 months or more for TB. The aim was to minimize the chances of migrants bringing sub-clinical TB into the country (MOH, 2010). Screening of migrants remains an important TB control strategy in identifying TB cases as immigration presents an opportunity for contact with migrants for TB screening (MOH, 2010). However, given that persons with latent TB infection have no or trivial evidence of TB, most cases of latent TB infection are missed. This raises concerns about the effectiveness of using chest-X ray in screening for TB, particularly, when the evidence suggests that migrants develop TB within the first two years post-arrival even after the mandatory screening (Public Health England & NHS England, 2015).

Part of the screening programme in NZ is that for quota refugees. Quota refugees are screened at designated offshore facilities aimed at identifying and treating those with TB before arrival in NZ. Upon arrival, refugees are screened again for TB at the Mangere Refugee Resettlement Centre, Auckland. Screening for latent TB infection among migrants is limited to only refugee children less than 16 years of age (MOH, 2010).

The current epidemiology of TB in New Zealand is one that shows high levels of disparity between the different ethnicities usually resident in NZ. In 2014, the incidence of TB among the Asian population was 34.1 per 100 000 population, for people from the

Middle Eastern/Latin American/African (MELAA) population it was 22.1 per 100 000 population, and for Pacific peoples the figure was 16.1 per 100 000 (Institute of Environmental Science and Research Ltd (ESR), 2015). The TB rates among people born outside the country (17.5 per 100,000) for 2014 alone was between two to three times higher than the national rate (6.2 per 100,000) and about 29 times the rate among European or “Other” ethnic groups (0.6 per 100 000) (Institute of Environmental Science and Research Ltd (ESR), 2015).

In reporting health data, level 1 classification (Asian, European, Māori, MELAA, Pacific Peoples and other ethnicity) of the ethnicity NZ standard classification is used for ease of categorization and reporting. These classifications reflect the geographic origins of the different groups living in NZ. While these categorisations are useful, they are broad, in some cases unrelated, and mask the real differences within the broad classification. For instance, the MELAA (Middle Eastern, Latin American and African) group consist of people from varied geographical locations with different health risks and cultures. Hence, to aggregate this group together and present summary health reports for them as if they were a homogenous group, due to their size in NZ, masks the existing health issues within the different populations. This has created a situation where health problems for smaller ethnicities like Africans are less prioritised. Again, the use of a prioritisation system in determining which ethnic group gets to be recorded for a person who specifies multiple ethnicities could result in lower priority ethnic groups being under-represented. This undermines the very idea of promoting self-identification of people, which remains central to the definition of ethnicity, and has implications for intervention and resource allocation (Bhopal, 2007).

The history of TB in New Zealand is one that has shown different phases from the time of its arrival into the country with the coming of the Europeans, through the period of its rise among the Māori, the compulsory notification of TB, the introduction of

antibiotic treatment, the HIV epidemic and the change in migration policy. The New Zealand government has made efforts to control TB in the past and continues to fight the disease in the present. However, there remain differences in the ethnic rates of the disease. With the introduction of the “New End TB Strategy”, with a global goal of pre-elimination of TB by 2035 (to reduce TB deaths by 95% and TB incidence by 90% compared to the 2015 figures) there remains more to be done (WHO, 2014).

2.3 Africans Living in NZ

In this study, the term Africans is used to represent people born in the sub-Saharan Africa region living in NZ. This definition was considered the most appropriate as it encompasses all persons who may be at risk of developing TB due to the high burden of TB in this region. In this context, the use of the term “African” was for categorization of people by birth place and not as an ethnic group, as not everyone born in this region may want to identify with the African ethnicity (Bhopal, 2007).

Earlier migration of Africans to NZ has been recorded from the early 1900s (Walrond, 2015). It was not until the 1990s, however, that the number of African migrants rapidly increased. Prior to this period migration from Africa was largely among the African born whites, who had the privilege of free movement between the British colonies, although, some black Africans emigrated in the 1960s to study (Walrond, 2015). The adoption of a formal annual refugee quota for the resettlement of refugees in 1987 and the introduction of the point based system following the passage of the Immigration Amendment Act 1991 led to a sharp rise in the number of African refugees and permanent residents settling in NZ (Immigration New Zealand, 2017; Walrond, 2015). The earliest Africans arriving in large numbers for resettlement together with other permanent residents were the Somalians in 1993 after the clan wars. Next were the Ethiopians who fled wars and famine (Walrond, 2015). Other large groups were from Zimbabwe between

2000 and 2003 following the implementation of the land reforms and the seizure of commercial farmlands along with the rapid collapse of the economy.

In the most recent census, a total of 72,084 people usually resident in NZ were born in sub-Saharan Africa (Statistics New Zealand, 2013b). This population has doubled between the two census points, 2001 (36,213) to 2013 (72,084), and is diverse, originating from over 40 countries in the region. South African born (75.3%) constitute the largest proportion of this group followed by those from Zimbabwe (11.2%), Kenya (2.3%), Zambia (2.0%), Ethiopia (1.6%), and Somalia (1.5%). All the remaining countries together constitute 6.1% of the total sub-Saharan African born living in NZ (Statistics New Zealand, 2013b).

2.4 TB in Sub-Saharan Africa: Epidemiology and Determinants

In 2015, the African region had the most severe TB burden per population (275 per 100,000), accounting for over a quarter (26%) of the total TB cases notified globally (WHO, 2016). Within the region, South Africa reported the highest estimated TB incidence rate (834 per 100,000), followed by Lesotho (788 per 100,000) and Mozambique (551 per 100,000). Most countries in sub-Saharan Africa have a high burden of TB, with over 150 annual incident cases per 100,000 population (WHO, 2016). Of the 30 countries designated as high TB burden countries globally – defined as the 20 countries with the highest absolute TB cases and the additional top 10 countries with the most severe burden of TB per population – 16 were within this region (WHO, 2015b). The region achieved its millennium development goal target of reducing TB incidence, albeit a slow decline between 1990 to 2015, but failed to achieve the target of reducing by half TB mortality by 2015 (WHO, 2015a). It had the slowest rate of decline (2.2%) in

TB mortality rate compared to the other five WHO regions from 2010 to 2015 (WHO, 2016).

The HIV epidemic has been an important driver of the TB epidemic and a major challenge to public health interventions aimed at reducing TB incidence and mortality rates in the region (Corbett et al., 2003). There exists an intimate association between HIV and TB. TB is the most common opportunistic infection and cause of death among HIV positive people living in low income countries, whilst HIV is one of the most potent risk factors for TB infection, reactivation of latent TB infection or rapid progression of acquired infection to disease (Corbett et al., 2003). The region continues to report the highest proportion of TB HIV co-infection rates, although variations exist across the different countries. In 2015, 31% of incident TB cases in the Africa region were HIV positive, with countries in southern Africa reporting the highest proportions of TB HIV co-infections: Lesotho (72%); Zimbabwe (69%); Zambia (60%); and South Africa (57%) (WHO, 2016).

Besides the HIV epidemic, the emergence and increasing trend in the proportions of TB cases resistant to anti-TB drugs is another challenge to public health action to eliminate TB in the region (Berhan, Berhan, & Yizengaw, 2013; Lukoye et al., 2015). Globally, the risk of MDR TB is higher among individuals previously treated with anti-TB drugs. For instance, in 2015, an estimated 3.9% of all new TB cases were MDR TB compared to 21% of previously treated cases being MDR TB (WHO, 2016). The African region has a relatively lower estimated incidence of MDR TB (New cases: 3.0%; Previously treated: 15%) than the global estimate (New cases: 3.9%; Previously treated: 21%) (WHO, 2016). In common with global patterns, recent studies in the region have demonstrated a rising trend in incidence and an increased risk of MDR TB among individuals previously treated with anti-TB drugs compared to new cases (Berhan et al., 2013; Lukoye et al., 2015).

Available evidence suggests that individuals living in countries with a high burden of TB are at an increased risk of acquiring TB (Rieder, 2003). Studies that conducted screening for latent TB infection and TB disease have demonstrated high yield following contact investigations of close contacts of persons with active TB (Guwatudde et al., 2003; Lienhardt et al., 2003; Morrison et al., 2008; Rieder, 2003; Zachariah et al., 2003). This high proportion of infections might be a glimpse of the pervasive TB epidemic in most African countries, where contact tracing is not a priority for TB control efforts, and strengthens the notion that migrants from Africa are likely to be exposed to TB in their countries of origin before migrating.

Whilst the risk of TB might be high at the community level for individuals living in the high burden countries within the region, it has been shown to be even higher for health care workers. Health care workers in the region are at an increased risk of TB compared to the general population, similar to other regions of the world (Baussano et al., 2011). One reason for the increased risk of TB among healthcare workers is the high likelihood of occupational exposure to TB. Previous studies have demonstrated higher annual new infection rates among health care workers than within communities (Adams et al., 2015; McCarthy et al., 2015). Poor enforcement of TB infection prevention and control policies and inadequate supply of personal protective equipment, coupled with overcrowding in health care facilities, high undiagnosed TB among patients and highly infectious TB patients have been identified as the other contributing factors to the high rates among healthcare workers (Grobler et al., 2016).

In sub-Saharan Africa, like all other regions of the world, poverty has been identified as a key determinant to the high burden of TB. The evidence suggests a strong socio-economic gradient within and between countries with impoverished neighbourhoods, communities and countries showing a high TB burden (Lönnroth et al., 2009). Poverty influences an individual's risk of acquiring TB including the effects of

malnutrition, overcrowding, late reporting and poor treatment outcomes (Barter, Agboola, Murray, & Bärnighausen, 2012; Lonnroth et al., 2010; Spence, Hotchkiss, Williams, & Davies, 1993). In sub-Saharan Africa, the impact of TB on economic conditions of households could be catastrophic (Ukwaja, Modebe, Igwenyi, & Alobu, 2012). The direct and indirect costs associated with the utilization of TB care services, including consultation/insurance fees, travel costs, time costs, food, and traditional healer/private provider costs, have been reported as significant contributors to the worsening economic conditions of affected individuals and households in some countries, with worse impacts for poorer households (Barter et al., 2012; Kemp, Mann, Simwaka, Salaniponi, & Squire, 2007; Ukwaja et al., 2012).

Early detection and treatment of TB are key intervention strategies for TB elimination. However, challenges of under detection, under reporting, delayed treatment initiation and non-completion persist globally (WHO, 2016). In the Africa region, the treatment success rate has shown an increasing trend from about 70% in 2000 to 81% in 2014, albeit lower than the expected target of 90%, whilst treatment coverage – defined as the gap between the actual notifications and the estimated incidence – in 2014 was less than 60% and the least among the six WHO regions (WHO, 2016). Existing evidence suggests that persons with TB are likely to delay in seeking treatment due to travel distance to health facilities and initial consultation to traditional healers (or private providers) (Finnie et al., 2011). Delay in seeking care is further linked to competing demands for scarce household resources (poverty), as most persons with symptoms suggestive of TB may defer visits to health providers by prioritizing resources for other high priority concerns (Finnie et al., 2011; Kemp et al., 2007; Sagbakken, Frich, & Bjune, 2008; Sanou, Dembele, Theobald, & Macq, 2004). High levels of stigma have also been implicated in the delays and undiagnosed TB within communities in the region (Daftary, 2012; Deribew et al., 2010).

Available evidence suggests that TB attracts negative stereotypes and is socially undesirable in most communities in the region (Daftary, 2012; Link & Phelan, 2001). In comparison, HIV bears the most negative stereotypes and is likely to invoke the highest level of stigma due to societal and cultural construction of the main modes of transmission as immoral or taboo and as a deadly disease (Daftary, 2012; Mbonu, van den Borne, & De Vries, 2009). The perceived confluence between TB and HIV, including similarities in symptoms such as weight loss, has contributed to the high stigma associated with HIV overlapping and causing double stigma for TB (Craig, Daftary, Engel, O'Driscoll, & Ioannaki, 2017; Daftary, 2012; Deribew et al., 2010). The high stigma may lead to hiding of symptoms, delayed reporting and non-disclosure.

Positive perceptions about TB at the community level and adequate knowledge have been documented in previous studies to influence early reporting (Storla, Yimer, & Bjune, 2008). National TB programmes in most sub-Saharan African countries have recognised the importance of individual knowledge about TB and have sought to provide health information and education as part of national TB control efforts. However, challenges with early reporting persist in most countries. Across the region of Africa, the level of education, socioeconomic status, personal experience, contact with healthcare providers, age, rural/urban location and the media have been suggested as important predictors of TB knowledge (Abebe et al., 2010; Amo-Adjei & Kumi-Kyereme, 2013; Buregyeya et al., 2011; Amare Deribew et al., 2010; Esmael et al., 2013; Mangesho et al., 2007; Naidoo et al., 2016; Tobin, Okojie, & Isah, 2013). The extent and direction of the association between these variables and TB knowledge may, however, vary between countries. For instance, while education (completion of high school) was identified as a strong predictor of high TB knowledge in South Africa (Naidoo et al., 2016), the converse was the case in Ghana (Amo-Adjei & Kumi-Kyereme, 2013), as higher education was positively associated with myths and misconceptions about TB (Amo-Adjei & Kumi-

Kyereme, 2013). Although variations exist across countries, available evidence suggests that general awareness about TB might be high within most communities in sub-Saharan Africa, (Abebe et al., 2010; Amo-Adjei & Kumi-Kyereme, 2013; Esmael et al., 2013; Naidoo et al., 2016). Some likely reasons for the high general awareness could be because of an individuals' own experience with TB (diagnosis and treatment) or through their encounters with close relatives or acquaintances within their communities who have been treated for TB. The findings also suggest a high level of TB awareness and HIV co-infection, and of TB as a curable disease (Abebe et al., 2010; Amo-Adjei & Kumi-Kyereme, 2013; Esmael et al., 2013; Naidoo et al., 2016). However, knowledge about symptoms have been shown to be inadequate in most countries, with some misconceptions identified on the causes, which has implications for delayed reporting, treatment initiation and worse treatment outcomes (Abebe et al., 2010; Amo-Adjei & Kumi-Kyereme, 2013; Esmael et al., 2013; Naidoo et al., 2016). In addition to contributing to delays in seeking help, the existing myths and misconceptions have contributed to the high sense of prejudice and fear about TB within some communities in the region (Amo-Adjei & Kumi-Kyereme, 2013; Amare Deribew et al., 2010; Dodor & Kelly, 2009; Tobin et al., 2013).

2.5 Summary

The chapter presented the clinical understanding of TB and a background discussion on TB in the two geographical areas of focus. It demonstrated that, TB rates in NZ were low compared to the African region. It also showed that globally, the African region had the highest TB burden and was likely to have high proportions of TB infection rates among the citizens, as evidenced by the few studies that have conducted TB infection screening during contact tracing. The chapter revealed that factors such as knowledge on TB, healthcare occupations, stigma, socio-economic circumstances of

individuals and treatment costs, influenced individual risks of acquiring TB and/or delay in seeking medical help for symptoms suggestive of TB. While these pertain to the African region, they are relevant in the context of the host countries as previous experiences may guide future actions. The next chapter will draw on the current chapter to show how these previous context factors might influence the behaviour of Africans in their new countries, and endeavours to show the epidemiology of TB and its determinants among Africans living in western countries by reviewing the available literature.

Chapter Three – Africans Living in Western Countries and TB

3.0 Introduction

In New Zealand and other low incidence countries (defined as less than 100 TB cases per one million population), TB elimination presents similar challenges. There are disproportionately high rates of TB reported among migrants from countries with a high TB disease burden (see section 2.2). Hence the migrant population, including those from sub-Saharan Africa are critical to eliminating TB.

The migrant population is not homogenous. It comprises of diverse cultures, beliefs and practices that may reflect the different countries of origin. Efforts to understand the unique characteristics of each sub-group are relevant for targeted effective interventions. Understanding the individual, social and structural factors that influence incidence and transmission of TB, particularly among migrants, may contribute to a better understanding of why rates of TB have plateaued in New Zealand (Das, Baker, Venugopal, & McAllister, 2006; Lönnroth et al., 2009). For instance, in the case of malaria, another infectious disease, Neave in her PhD thesis demonstrated that individual, social and structural factors were relevant in influencing health action of Nigerian and Ghanaian migrants living in London (Neave, 2013). Thus, this study will explore how these range of factors might influence TB incidence among African migrants living in NZ.

The focus of this chapter is to review the current literature and set in context what is already known about TB among African migrants living in western countries, with a focus on the factors that are likely to increase vulnerability to TB leading to the relatively high rates of TB among them. The chapter begins with a definition of “migrant” and

further describes: the systematic literature search and review of included studies; the epidemiology of TB among African migrants in western countries; the main determinants of TB among African migrants living in western countries with a focus on personal, economic, social and structural factors and; ends with a broad review of TB control strategies of other comparable countries including Australia, Canada, US (focused on New York city) and UK.

3.1 Definition of a Migrant

In this thesis the five main groups of migrants, according to the definition by Reider and colleagues, will be adopted for use (Rieder, Zellweger, Raviglione, Keizer, & Migliori, 1994). This definition has been used in recent times in systematic reviews for TB among migrants in low incidence countries (Aldridge et al., 2014; Klinkenberg, Manissero, Semenza, & Verver, 2009).

Migrant: A foreigner legally allowed in a country and expected to settle in that country

Asylum seeker: A foreigner, who wants to be permitted to stay in a country as a refugee and is waiting for a decision on an application for refugee status according to appropriate international protocols

Refugee: A person fleeing persecution or conflict who meets the refugee definition of the 1951 Convention related to the Status of Refugees and its 1967 protocol, or of other relevant international or regional instruments

Foreign-born citizen: A foreigner, who has become a national or citizen of a host country in which they presently live but who originally was born in a different country

Undocumented Foreigner or Migrant: A foreigner, who has entered, is staying and/or working in a country without a visa or permit

These definitions were applied to persons of sub-Saharan African origin living in western countries. The four types of migrants, as defined and used in this review, offered a much broader scope than would a narrow definition and hence the likelihood that as many studies as possible were identified from the search for current literature.

3.2 The Literature Search

The literature search was systematically conducted by searching the databases EBSCO Health, CINAHL, MEDLINE and in MEDLINE via PubMed for relevant studies. The selection of these databases was most appropriate for the study topic, given that they provide a collection of studies in nursing, allied health, medicine, health, biomedicine and some behavioural sciences. Searches in these databases offered the assurance that a wide collection of studies would be searched and relevant articles would be identified for review. Search terms used were key words and their derivatives that captured their meaning and included: “Tuberculosis”, “Africa”, names of some western countries (UK, US, Canada, Australia, NZ, Norway, Holland, Italy), “migrant”, “interventions”, “prevention”, “control”, “treatment”, “adherence”, “delay”, “knowledge”, and “barriers”. References of selected articles were reviewed for additional studies. Given the focus of the study, to understand the reasons for the relatively high TB rates among African migrants living in Western countries, the search was limited to studies conducted in Western countries and published in English within the last 15 years (from the year 2000 to 2015). Only studies published in English were included for ease of understanding, and to save time and the limited resources from needing translation services. Again, the 15year period inclusion criteria was to ensure that enough literature on the relevant TB issues from the turn of the 2000s to the most recent were included. Excluded studies were duplicates of the included studies, were not conducted in Western countries and did not specifically present findings for African migrants.

The initial search produced 641 articles, which were initially screened by title and abstracts. Seventy-six articles were chosen for further review. The full articles of these studies were reviewed and 22 included. Studies selected for inclusion were classified under the two broad categories – quantitative epidemiological studies (n=15) and qualitative studies (n=5) exploring the determinants of TB – data were extracted for analysis and synthesised accordingly.

3.3 The Epidemiology of TB among African Migrants

Of the 15 studies included, only two presented data describing the specific characteristics of persons of African descent living in Western countries diagnosed with TB. In most cases, the description has sought to include African migrants as part of the migrant population in a country, thus not providing detailed information about the characteristics associated with TB specific to persons of African origin. Details of the 15 studies included in describing the African TB epidemiology are provided in table 3.1.

Table 3.1:
Details of Included Studies

	Authors (year)	Country	Methods	Participants and other details
01	Borgdoff et al. (2000)	US	Molecular epidemiological study	All culture positive TB cases reported from January 1991 through December 1996 in San Francisco county
02	Kempainen et al. (2001)	US	Retrospective epidemiological review	All Somali immigrants notified with TB disease living in Minnesota from January 1, 1993 to June 30, 1998
03	Varkey et al. (2007)	US	A retrospective epidemiological analysis of screening data	Primary refugees arriving in Minnesota from January 1, 1997 to December 31, 2001.
04	Abraham et al. (2013)	US	Epidemiological analysis of TB surveillance data, categorized into three groups: US born, Africans and other foreign born	All TB cases reported to national TB surveillance system (NTSS) from January 1, 2000 to December 31, 2009 by the 50 states
05	Howie et al. (2005)	NZ	Retrospective epidemiological review of TB surveillance data	All children less than 16 years notified of TB within the period of January 1, 1992 and June 30, 2001 from nine health districts
06	Das et al. (2006)	NZ	Epidemiological study based on analysis of surveillance data	TB cases recorded in the national surveillance system from 1995 to 2004
07	Farah et al. (2005)	Norway	Epidemiological analysis of TB surveillance data by matching TB data with immigration registry	All immigrants notified of TB within the period of 1986 – 2002 of whom date of arrival was recorded

08	French et al. (2009)	UK	Analytical epidemiological study	TB cases reported during the period of 2000-2005 in the enhanced TB surveillance system
09	Garzelli et al. (2010)	Italy	Molecular epidemiological analysis	TB strains isolated from TB patients born in Italy and foreign born reported in Tuscany within the period 1 st January 2002 to 31 st December 2005
10	Jansen et al. (2012)	Canada	Epidemiological study of TB surveillance data.	Population of Canada living in the Alberta province notified across two decennials (1989-1998 and 1999-2008).
11	Creatore et al. (2005)	Canada	Population-based retrospective cohort study	All TB cases notified between 1990 and 1997 in the Ontario province
12	Kan et al. (2013)	Sweden	Epidemiological study	415 patients treated for latent TB infection at Karolinska University at Stockholm from March 2002 to December 2007
13	Gibney et al. (2008)	Australia	Retrospective clinical data analysis	TB patients born in sub-Saharan African visiting Royal Melbourne hospital from 1 st January 2003 to 30 th June 2006
14	McPherson et al. (2008)	Australia	Epidemiological study	Foreign-born persons living in Victoria, diagnosed with TB between 1990 and 2004
15	McBryde et al. (2012)	Australia	Longitudinal study	All immigrants arriving between 1975 and 2007 and notified of TB within 1995 to 2010

3.3.1 TB Rates

The available evidence shows that TB rates are disproportionately high among African migrants living in Western countries (Abraham, Winston, Magee, & Miramontes, 2013). Although the population of African migrants are relatively small, they account for significant numbers of TB cases and the national rates of TB in Western countries (Kempainen, Nelson, Williams, & Hedemark, 2001). The available evidence shows that, in NZ, African migrants contributed 6% (16 cases) of the new TB cases reported in 2013

(264 new cases), with a population of just 1.6% (72,084) of the total NZ population (4.4 million) (Statistics New Zealand, 2013a), representing an incidence rate of 27.1 per 100,000, which was about 15 times the rate among persons born in NZ (1.8 per 100,000) (Institute of Environmental Science and Research Ltd (ESR), 2015).

A similar trend was observed in Canada where black Africans represented 2.9% of the Canada population (Statistics Canada, 2011) yet contributed about 9% of the total TB cases reported in 2013, and had the highest TB incidence rate of 48.5 per 100,000 among the non-Canada born population (Public Health Agency of Canada, 2015). In the UK, in 2013, the rate of TB among non-UK born Africans (170 per 100,000) was over 40 times the rate among the UK-born population (4 per 100,000), and was the highest rate among the non-UK born population after Pakistani and Indian sub-population groups (Public Health England, 2014). The picture was no different in Australia in 2013, where the incidence rate among the Australian born population was 1.0 per 100,000 whilst that for foreign-born people was 18.4 per 100,000. The rate for foreign born persons, like the other countries mentioned, equally showed disparities among the different countries of birth, with the highest rate being among persons born in Somalia (243 per 100,000), which was over 240 times the rate of the Australian-born population (Toms, Stapledon, Waring, Douglas, & National Tuberculosis Advisory Committee, 2015).

This has been the trend in previous years. In New Zealand, between 1995 and 1999 the highest rate of TB for foreign and local born, was among persons born in Ethiopia (320.9 per 100,000) and Somalia (1924.4 per 100,000) (Das, Baker, Venugopal, et al., 2006). Among children, African children less than 16 years had the highest rate of TB in NZ between the period of 1992 and 2001 with an annual average rate of 575.2 per 100,000 (Howie et al., 2005). In Norway, the proportion of cases within the period 1986 to 2002 was highest among Africans, especially among Somalians (Farah, Meyer, Selmer, Heldal, & Bjune, 2005). A similar trend has been shown in Italy, where from 2002 to

2005, the highest rates of TB among foreign born persons were from Africa (Garzelli, Lari, Cuccu, Tortoli, & Rindi, 2010).

TB rates among Africans are not only highest among persons born overseas, the evidence shows it might be increasing. In Canada, from 1989 to 2008, the rate of TB was shown to be increasing among persons born in Africa unlike other foreign-born immigrants and the persons born in Canada in whom rates of TB decreased over the same period (Jensen et al., 2012).

3.3.2 Patient Characteristics

The available literature suggests that most African migrants diagnosed with TB are more likely to be younger (mean age=31.8 years) compared to other non-African TB patients (mean age of other foreign born=44.1 and US born=47.5 years) (Abraham et al., 2013; Farah et al., 2005; Kempainen et al., 2001) and are more likely to be diagnosed within the first five years of arrival, like the other migrants. However, compared to other migrants, most Africans are likely to be diagnosed within the first year of arrival, sometimes within three months of arrival, with the rates decreasing from the second year of arrival (Kempainen et al., 2001). In Minnesota, for example, a study showed that 30% of the study population began treatment three months into arrival in the US, while over half were diagnosed and started treatment within the first year of arrival, and 83% diagnosed within the first two years of arrival (Kempainen et al., 2001). This was similar in New Zealand (Das et al., 2006) where more than a quarter (28.3%) of migrants from high incidence countries who had TB within the first year of arrival were diagnosed within the first two months of arrival. The same pattern has been shown in Australia (McBryde & Denholm, 2012), Canada (Creatore, Lam, & Wobeser, 2005) and Norway (Farah et al., 2005). Although the rates are higher within the first five years of arrival,

peaking within the first two years, the incidence rates remain high among African migrants, even ten years on after arrival, compared to persons born in the host countries (McBryde & Denholm, 2012; McPherson, Kelly, Patel, & Leslie, 2008).

Among African migrants, refugees are the most likely to be diagnosed with TB within the first few months of arrival (Varkey, Jerath, Bagniewski, & Lesnick, 2007). This refugee group has the highest risk of TB likely due to the difficult migration conditions that some endure before arrival in their host countries (Dhavan et al., 2017; Johnson & Ellner, 2000). Just like other migrants, the high TB burden in their countries of origin predisposes them to latent TB infection. In the case of refugees, however, factors such as the stress of displacement, malnutrition and crowded living conditions in refugee camps prior to their travel, and the stressful living conditions in their host countries, especially within the first few months of arrival exposes such individuals to increased risk of TB infection and progression to TB disease (Dhavan et al., 2017; Johnson & Ellner, 2000).

African migrants diagnosed with TB are also more likely to have positive results for HIV (14.4% positive) compared to other non-African foreign-born TB patients (4.5% positive) (Abraham et al., 2013). This is most likely due to the relatively high rates of HIV in Africa (Corbett et al., 2003; WHO, 2016). An analysis of TB rates among Africans living in the US by region of birth has indicated that individuals with TB from the countries of highest HIV prevalence, mostly in the southern Africa region, had the highest proportion of HIV TB co-infections (45% of all TB cases from southern Africa were HIV positive), compared to those from other regions of the continent (Central, 26% HIV positive; West, 16%; East Africa, 9%; and North, 5%) (Abraham et al., 2013). A gap in the literature exists, as few studies have provided a description of the demographic characteristics and other risk factors associated with TB among African migrants.

In addition, the available evidence suggests that the proportion of extra-pulmonary TB is relatively high among African migrants (31.4%) compared to other non-African TB patients (other foreign born, 22.1% and US born, 17.2%) (Abraham et al., 2013). Patients from East Africa (35%) have been shown to have large proportions of extra-pulmonary TB (Abraham et al., 2013). The reasons for the high extra-pulmonary TB among Africans, especially East Africans, are not clear. It has been suggested that the differences in immune response and the genetic make of the bacilli may explain why some persons might develop extra-pulmonary TB. For instance, it has been suggested that the East African-Indian *Mycobacterium tuberculosis* lineage, which is predominant in East Africa and India, is associated with extra-pulmonary TB and may explain why this type of TB is relatively high in East Africa (Albanna et al., 2011).

3.3.3 Geographic Distribution

There is a paucity of literature on the geographical distribution of persons with TB of African descent living in Western countries. The only published study identified from the search that had specifically analysed this was by Abraham and colleagues in the US. They showed that most African TB patients were living in major cities, which corresponded with patterns of immigration. They also showed the proportion of cases most likely corresponded with the rates of TB of the regions of Africa from where patients migrated, the highest proportion coming from the East Africa region, which accounted for more than half (58.2%) of all TB cases from their study (Abraham et al., 2013).

An analysis of migration patterns and geographical location of African migrants living in NZ, including persons of African origin with TB, would contribute to filling the gap in the literature. This would provide some understanding of the determinants of TB within African migrant communities.

3.3.4 Transmission of TB

Available evidence from molecular epidemiological studies, which investigate the genetic and other environmental determinants of TB at the molecular level to understand the disease aetiology, suggest on-going transmission of TB among African migrants, although the highest proportion of cases is likely due to reactivation of remotely acquired LTBI (Borgdorff, Behr, Nagelkerke, Hopewell, & Small, 2000; Yen, Bower, Freeman, Basu, & O'Toole, 2013). Studies using molecular epidemiology have observed that not all cases of TB among African migrants resulted from acquisition in their countries of birth (Borgdorff et al., 2000; Garzelli et al., 2010). Borgdorff and colleagues demonstrated that, among African immigrants, recent transmission of TB was from an African source; and among the foreign-born cases studied, the highest transmission index was among Africans within the young adult age group, with persons aged less than 35 years having the highest rate of transmission. Transmission among the young adult age group would most likely result in sustained rates of TB over a long period (Borgdorff et al., 2000). The few who acquire the bacilli may develop TB disease immediately or otherwise within a short period, while others may remain infected and continue to develop active TB in later years of life, serving as reservoirs for TB disease. This, might sustain the rates among the African migrant population over an extended period (Crofton et al., 1999).

TB among children shows on-going transmission of the disease within a community and undetected TB among adults, who serve as the source for transmitting the bacilli to children (Howie et al., 2005). In NZ, during the period of 1992 to 2001, the highest annual rate of TB among children under 16 years was among Africans (Howie et al., 2005). This shows most likely that, within the African community, there was continuous transmission of TB from unidentified African adult TB sources. Of significance in this finding was the high rate of TB among the 0-4 years age group within

this population sub-group. This raises concern about the delays in seeking care and the general effectiveness of TB control in identifying cases of active TB and starting treatment in time: early enough to reduce onward transmission of TB among this group.

3.4 The Determinants of TB

Migrants living and working conditions, their social and economic circumstances as well as personal and even legal status can affect their vulnerability to TB (Dhavan et al., 2017; Lönnroth et al., 2009). These factors may also affect how one may progress from infection to developing active TB. It is likely that most migrants from Africa may be exposed to the bacilli prior to migration and so may have latent TB upon arrival in NZ. For instance, a systematic review and meta-analysis of household contact investigations conducted in the Africa region found a pooled yield of 50.5% for latent TB infections (Morrison et al., 2008).

The decline of TB cases in Western countries since 2000 remains slow, which partly confirms the sustained vulnerability to TB among the most at-risk groups (Lönnroth et al., 2009). This slow decline may be a reflection that the underlying factors or the cause of the causes still exist and, in some cases, may be getting worse.

The overemphasis on the biomedical model – the individual biological factors – rather than prevention in TB control over the years is reflected in the paucity of published articles in current literature on the role of the social determinants in TB acquisition and transmission, particularly among vulnerable groups. The review of available literature, described above, identified seven qualitative studies, most of which were conducted in the UK, corroborating the point that, although African migrants are an important sub-group in some Western countries in relation to TB disease, little has been done to

understand the cause of the causes of TB among this vulnerable group. A summary of the details of the included studies is provided in table 3.2.

Table 3.2

Details of included qualitative studies

No.	Authors (year)	Country	Methods	Participants and other details
1.	Nnoaham et al. (2006)	UK	Semi-structured Interviews	16 African born adults aged 18 years and above who attended Homerton university hospital in Hackney, East London for treatment of TB
2.	Gerrish et al. (2013)	UK	Focused ethnographic approach using individual interviews	14 Somali TB patients and 18 healthcare workers living in Sheffield
3.	Gerrish et al. (2012)	UK	In-depth interviews, semi-structured interviews and focus group discussion	10 community leaders, 8 members of the Somali community, 14 TB patients who were receiving or had completed treatment recently living in Sheffield
4.	Sagbakken et al. (2010)	Norway	Individual semi-interviews	22 immigrants from Somalia and Ethiopia diagnosed with TB living in the city of Oslo and within the Akershus county in Norway
5	Shetty et al. (2004)	UK	Cross sectional using questionnaires	23 TB patients, 25 contacts (family members) and 27 other members of the Somali population as control. All respondents were living in inner London.
6	Van de Oest et al. (2005)	New Zealand	Individual interviews	Seven representatives, one each from the 7 main minority population groups living in Waikato; Somalia, Cambodia, China, Cook Islands, Māori, Philippines and Samoa

7	Asiimwe et al. (2015)	UK	Face to face interviews	12 non-UK-born black Africans aged >18years with no clinical symptoms of TB living in Leeds
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3.4.1 Personal Factors

3.4.1.1 *Knowledge, attitudes and beliefs about TB*

The response of individuals to symptoms suggestive of TB disease are greatly influenced by their knowledge, attitudes and beliefs (Jenkins, 1966; Westaway, 1989) and these factors remain critical in early reporting, treatment adherence and referral of other people for treatment.

Knowledge about TB has been shown to be varied among African migrants. While some migrants had good knowledge of the biomedical explanation of TB (e.g. TB as airborne, could be acquired when one breathes in the TB germ, which can be passed to other people), others held different perceptions such as TB being hereditary: “there is inherited TB, it will stay with you forever, your grandfather had it, then your father, then you” (Gerrish, Naisby, & Ismail, 2012, p. 2657 participant quote). To some African migrants, TB may result from the complication of other minor illnesses, which are left untreated, from poison, sharing of utensils or cutlery of infected people, filth, cold, dust and sex (Asiimwe, Cross, & Haberer, 2015; Gerrish et al., 2012; Nnoaham, Pool, Bothamley, & Grant, 2006; Sagbakken, Bjune, & Frich, 2010). Other perceptions about the cause of TB relate to the socio-economic status of people including hunger, poor diet and excessive physical and psychological stress. Among some African migrant communities there may be the perception that TB is the disease of “low-class people, a low-class disease. Because low-class people they don’t get food that is good and they are exposed to many things” (Sagbakken et al., 2010). While such notions may be valid, as

poor living conditions are associated with TB, they have the tendency to create a perception of low susceptibility to TB among many African migrants in their host countries and may likely result in delays in reporting for help. Such individuals may start treatment but might abandon it when they begin to feel better, believing that the disease they had was not TB (Sagbakken et al., 2010).

At the community level, negative perceptions of TB may fuel stigma and discrimination, which may have consequences for symptom identification, early reporting and treatment adherence (Craig et al., 2017; Link & Phelan, 2001). An individual's beliefs about his/her vulnerability (susceptibility) to a disease condition and the severity of the disease is more likely to influence a positive health action, according to the health belief model (HBM), which is a model for understanding individual health behaviour based on their personal beliefs (Janz & Becker, 1984). The HBM further explains that the risk perception of individuals therefore may be directly related to their knowledge of the condition. In this case, their level of knowledge about TB disease could be an important trigger of a positive health behaviour. However, this may not always be the case as having adequate knowledge may be subject to other conditions beyond the individual in shaping his/ her actions (Janz & Becker, 1984).

Although some African migrants have been shown to know about TB treatment and the length of time required for treatment (Shetty, Shemko, & Abbas, 2004), the belief that TB is hereditary has led some to the belief that, even after treatment, one cannot be fully cured (Gerrish et al., 2012). With this perception, persons diagnosed with TB are more likely to be labelled by other members of the community as infectious for the rest of their lives; and for migrants, it may be the case that their family in Africa could also be stigmatised if people hear about their infection. Precautions may be taken by people around known persons with TB during and even after treatment to avoid being infected. This has implications for accessing healthcare and patient disclosure, which can fuel

transmission of the disease as people delay in seeking care for fear of being isolated or discriminated against for the rest of their lives (Gerrish et al., 2012; Nnoaham et al., 2006).

The attitudes of some persons of African origin have been shown to be shaped by the social stigma attached to TB, which has its roots in the pre-medication era, when TB treatment was not readily available (Craig et al., 2017; Gerrish et al., 2012). To some, TB is shameful, a disease of filth and a consequence of bad acts committed by people (Gerrish et al., 2012). There are implications of this for identifying and screening of contacts of TB cases, which is one of the mainstays of TB policy in NZ (MOH, 2010). People diagnosed with TB may be less willing to disclose names and correct addresses of close contacts who may need to be screened, for fear that people may know their status.

A major limitation in the studies included in this review is the generalization of the study findings to reflect the entire African migrant community in their host countries. The included participants were mostly Somali and Ethiopian and do not represent the diverse ethnicities from Africa. African migrants are not a homogenous group, even the sub-ethnicities like Somali are very diverse and, as such, any generalization of findings, especially from qualitative studies, must be read with caution as rightly admitted by some of the included studies (Gerrish et al., 2013; Sagbakken et al., 2010). Additionally, included studies mostly recruited study participants through the health care system, through their nurses, which could have limited the findings as there may be other individuals with TB who may not be engaged with the health system and could have provided other information to strengthen the findings.

There has been little work done so far exploring the socio-cultural meanings of TB to African migrants in western countries. This remains important, particularly in the New Zealand context, where TB among Africans remain high, significantly contributing

to the overall national rates. Moreover, given that there is no published work so far in New Zealand exploring the meanings of TB to African migrants, it is imperative that more research is conducted in this area.

3.4.1.2 Diagnosis process: Prior diagnosis

Studies on the interpretation of initial TB symptoms by TB patients of African descent have yielded mixed findings. Some correctly identified some of the initial symptoms as TB, whilst to others the perception that TB was a severe disease meant the initial symptoms were not considered severe enough to be TB (Sagbakken et al., 2010). They may attribute initial symptoms to normal cold, food poisoning or excessive physical activity and may want to report much later when the symptoms are severe such as a persistent cough, weight loss and weakness (Nnoaham et al., 2006; Sagbakken et al., 2010).

The interpretation of initial symptoms may also be informed by the low risk perception of some African migrants. Some held the belief that TB was only for poor countries and hence living in a developed country meant they were not at risk (Sagbakken et al., 2010). Some migrants, in denial, may find other reasons to justify not responding to the symptoms and may not seek care. For instance, the fear of being correctly diagnosed and negatively labelled, may push some to conceal or ignore their symptoms. Whilst others, owing to their low risk perception and lack of knowledge, may not consider TB as a possible cause for their initial symptoms (Sagbakken et al., 2010). They may resort to pain killers and other remedies to reduce their pain, but may serve as a source of infection for their close contacts.

There may also be considerable anxiety among individuals before diagnosis because of the uncertainty about their symptoms (Gerrish, Naisby, & Ismail, 2013). For

some individuals, the longer the period of diagnosis the more worried or stressed they may become, possibly due to the negative stereotypes associated with TB within the community (Craig et al., 2017; Gerrish et al., 2013). In some cases, some individuals during this period of wait may withdraw from their social networks to keep to themselves. Their intention might not be to prevent transmission of the bacilli to other susceptible individuals, but to avoid people from identifying or suspecting their condition (Gerrish et al., 2013).

Little work has been done to explore TB risk perception of persons of African origin living in Western countries in the light of their transition to their new countries. This is important, as early diagnosis and treatment of TB to stop transmission to other susceptible individuals remains the cornerstone of TB control.

3.4.1.3 Diagnosis

Among African migrants, it has been reported that most persons diagnosed with TB have had to make repeated visits to their GPs before being diagnosed (Gerrish et al., 2012, 2013; Nnoaham et al., 2006; Sagbakken et al., 2010). Reporting with obvious symptoms and medical history suspicious of TB is more likely to lead to an early diagnosis, whereas diagnosis may likely be delayed for several months for individuals who may have extra-pulmonary TB (Gerrish et al., 2013; Sagbakken et al., 2010).

Health professionals in most cases may not consider TB as the likely cause of illness for persons born in Africa during their first visit for care. Some Africans have reported being given pain killers and antibiotics on their first visits (Sagbakken et al., 2010). Some finally got diagnosed correctly with TB months after their initial contact with healthcare providers, having been treated and in some cases repeatedly treated for common cold, malaria and pneumonia. It has been reported that, some Africans with TB

who did not feel better after treatment for other conditions, impressed on their GPs to consider other conditions (Sagbakken et al., 2010). Most of these migrants felt humiliated as their GPs insisted that they most likely did not respond to treatment because they were stressed or depressed, repeating the treatment and asking them to rest (Sagbakken et al., 2010). The power imbalance between GPs and African migrants may play a significant role in diagnosis of TB. There is the need for more work to be done to understand such relations. Questions such as, the perception of GPs about African migrants' knowledge about TB and its symptoms, and the role lay perception about TB symptoms may play in influencing diagnosis of TB, need to be explored.

The length of time taken from first visit to diagnosis and the accompanying wrong prescription has been reported to lead to people's frustration and mistrust of their GPs (Gerrish et al., 2013; Sagbakken et al., 2010). Persistence of the pain and discomfort associated with the disease, leads some people whose diagnosis are delayed to "shop for care" by visiting several GP centres until they find treatment to soothe their pain. Individuals who are unable to "shop for care" due to cost are most likely to be more anxious, not knowing what the cause of their disease may be (Gerrish et al., 2013).

Factors such as language present a barrier between people and their GPs and have been attributed to delays in diagnosis (Nakiwala et al., 2017). Individuals who have difficulty in expressing themselves in the language of their host countries may not be able to describe clearly the symptoms of their disease (Gerrish et al., 2013). The level of suspicion among GPs for TB, dependent on the number of cases seen, the frequency of cases and the TB awareness of GPs, affects TB diagnosis (Gerrish et al., 2013). GPs have reported that they are more likely to suspect TB as a possible cause of illness and seek to rule it out when they tend to see more TB cases or high-risk groups in their practice (Gerrish et al., 2013). But they may not readily suspect TB in most cases when they rarely see TB cases or high-risk groups in their practice. It has been indicated among some GPs

that the focus on identifying other possible causes of the symptoms and signs presented by people, other than TB, is what most likely delays the diagnosis (Gerrish et al., 2013). This has implications for a diverse health workforce that reflect the demographics of the country. Improving the workforce diversity could contribute to reducing the health system delays, as health professionals from countries with a high TB burden may be more likely to have some experience with TB in their practice life and hence more likely to suspect TB cases.

3.4.1.4 Post diagnosis

As highlighted earlier, there is little published work on the experiences of African migrants in Western countries in relation to TB and its diagnosis. The available evidence suggestss some persons with TB report some relief after knowing their status while many others go through psychological distress for fear of the consequences of the disease on their social life (Gerrish et al., 2013). African migrants are more likely to disclose their TB status to their immediate family but are unlikely to disclose to other people. Likewise, family members are unlikely to disclose to other people outside their immediate circle, perhaps due to the misconception that TB is a familial disease (hereditary) and hence the perceived shame associated with the disease is not limited to the individual but every member of the family.

After diagnosis, some individuals are more likely to experience stigma. They may have the feeling of being stigmatised; either imposed on themselves or from actual experiences from other people in their communities (Nnoaham et al., 2006). The stigma may most likely be due to poor knowledge of TB and the belief held by people that TB is a serious disease, which could easily be transmitted (Nnoaham et al., 2006). It has also been reported that the stigma felt by persons with TB may be compounded by the

perception of some African migrants that symptoms such as weight loss and coughing are associated with HIV (Nnoaham et al., 2006). The effect of transferring the negative stereotypes from HIV to TB could be that African migrants might refuse HIV testing and conceal their TB diagnosis (Daftary, 2012).

There seems to be an improvement in the stigma associated with TB in some African migrant communities as knowledge on TB improves (Gerrish et al., 2013). However, as Gerrish and colleagues (2013) indicated, much research needs to be done as there still exists a sizeable number of African migrants who may be horrified when diagnosed with TB.

3.4.1.5 Treatment experiences

The available literature suggests that most individuals of African origin with TB have faith in the current treatment regime for TB and report feeling better after taking the initial doses of their treatment (Gerrish et al., 2013). The benefit of this to affected individuals may be their ability to resume some normal activities and to get back into their social networks of friends and family, although some of them remain isolated. While the reintegration may be helpful, some affected individuals interpret their feeling of wellness to believe they are cured and are likely to abandon treatment (Gerrish et al., 2013). The support of close family and healthcare professionals have been acknowledged as important for Africans with TB in adhering to treatment (Gerrish et al., 2013).

Some individuals with TB of African descent have reported economic hardship during treatment (Gerrish et al., 2013), which may be worsened by already poor living conditions, poor food intake and poor or non-existent social support. While most individuals diagnosed with TB may lose some income due to the loss of work hours, the

most seriously ill persons might be the most affected as they may take some appreciable time to feel better and to engage in any work (Gerrish et al., 2013).

Even after completing treatment and being confirmed as cured of TB, some individuals may have difficulties in seeking employment for fear of rejection, stigma or bad treatment by their former employers and/or colleagues and may take a much longer time to secure a job again (Gerrish et al., 2013). Some may resought to seeking employment in other areas of work, which could be challenging for them. Little work has been done to explore work life of persons with TB after treatment. This is even more important given that work colleagues of persons with TB are likely to be screened as contacts during contact tracing by health professionals. What then could be the response or attitude of the colleagues or even employers to the cured individuals when they return to work after treatment?

Although, as noted above, it has been reported that most Africans with TB believe in TB treatment and are likely to complete treatment (Abraham et al., 2013), some individuals are unlikely to believe they are fully cured even after completing treatment (Gerrish et al., 2013). Informed by this misconception, some affected persons may isolate themselves for fear that they may still be infectious even after successful treatment completion. The family and close relatives may likewise avoid resuming interactions with some affected but cured individuals. Not much literature exists on the life of African migrants cured of TB in the longer term after treatment. This needs to be studied to inform interventions to dispel notions held by communities.

The interval between on-set of symptoms and treatment has been found to be longest for the most deprived persons (French, Kruijshaar, Jones, & Abubakar, 2009). In UK, it has been observed that there exists a strong association between deprivation and ethnicity and the interval to start of treatment. The longest interval to treatment was

observed among the most deprived black Africans who had been in the UK for less than two years (French et al., 2009). It has been indicated that the initiation of care-seeking may be inhibited by the initial cost of GP services and the cost of and unreliability of transportation services (van der Oest, Chenhall, Hood, & Kelly, 2005). Other factors, such as cultural differences and expectations of migrants, have been reported as reasons for delay in starting treatment (van der Oest et al., 2005). How comfortable migrants may feel on their visit to GP centres and the competence of health staff to deliver culturally appropriate care to people may influence treatment seeking behaviour of migrants (van der Oest et al., 2005). Similarly, the organization of health services, knowledge about the healthcare system and country of origin of GPs have been reported as likely causes of delay in seeking treatment for TB in New Zealand (Anderson, 2008). These findings support the argument that, while most African migrants may be aware of TB and might believe in the available treatment, their decision to report symptoms suggestive of TB early enough depends of several other factors beyond their direct control.

The correlation between TB treatment delay and TB transmission seems logical given that individuals with TB may continue to expel the bacilli. This association has been shown to be true by a study by Golub and colleagues after they analysed data of close contacts of persons with infectious TB who delayed in seeking treatment (Golub et al., 2006). They found that close contacts of persons with TB who were US-born and had delayed treatment over 90 days were more likely to have latent TB infection measured by tuberculin skin test, or TB disease than close contacts of persons with TB who had short treatment delays (OR 2.34; P=0.03). For contacts of foreign born persons with TB, there was no significant association between tuberculin skin test positivity and TB disease and treatment delay. The study had some limitations, including incomplete data for contacts, and not identifying or testing 22% of contacts of persons with TB included in the study. The effect of this could be significant on the outcome of the study. Delaying treatment

for persons with TB has public health implications both at the individual level and for the community. For an individual, it increases the risk of death from TB while at the community level, especially for persons with pulmonary TB, it increases the risk of transmission of TB to other susceptible individuals in close contact (Virenfeldt et al., 2014). Understanding factors that contribute to TB treatment delays, particularly among African migrants, is important for TB prevention and treatment interventions.

3.4.2 Risk Factors

3.4.2.1 The poverty complex

Poverty has long been associated with TB and remains an important risk factor for TB infection and TB disease (Fairchild & Oppenheimer, 1998; McKeown & Record, 1962). It is closely linked to overcrowding, which directly increases the risk of exposure to the TB bacilli (Lönnroth et al., 2009). Similarly, poverty influences nutrition and other lifestyle choices of individuals, which may compromise the body's defence mechanism leading to individuals progressing from TB infection to disease (Lienhardt, 2001; Lönnroth et al., 2010).

The term 'poverty complex' (Crofton et al., 1999) is used in this thesis to show the difficulty and complexities in understanding how poverty is associated with TB. Poverty may be defined or assessed by other factors such as unemployment, low income, poor housing, overcrowding and malnutrition among others (Lienhardt, 2001). These factors are interlinked and difficult to study without one influencing the other. Due to these complexities, most studies have sought to understand the association of poverty or deprivation with TB using ecological studies. Ecological studies are those that have an area rather than an individual as the "unit of analysis", which makes it possible to compare areas with varying levels of deprivation. In NZ, this can be achieved by using census area

units or mesh blocks as measured by the New Zealand deprivation index (NZDep2013), and these indices of deprivation exist in many other Western countries too. Ecological studies, by themselves, do not provide a conclusion of causality (Cegielski & McMurray, 2004); they suggest causal links or hypotheses for further investigation. The value of such studies, although inconclusive, is the knowledge they provide.

The available evidence suggests that the incidence of TB is likely to increase with increasing neighbourhood poverty (Barr, Diez-Roux, Knirsch, & Pablos-Méndez, 2001). In their attempt to understand the likely causes of the resurgence of TB in New York in the 1980s and 1990s Barr and colleagues noted a linear rise in TB incidence as neighbourhood poverty increased leading them to suggest that poverty may be the most likely factor in explaining TB incidence rather than race, ethnicity or foreign birth (Barr et al., 2001). Some studies tend to disagree with this finding and have found transmission of TB to be associated with ethnicity or minority race and immigration (Myers, Westenhouse, Flood, & Riley, 2006).

In the UK, Bhatti, Law, Morris, Halliday, and Moore-Gillon (1995) analysed national TB data of England and Wales from 1980 to 1990 to examine if TB incidence was higher in deprived areas. Additionally, data from 1986 to 1993 from Hackney, a socioeconomically deprived London borough with large communities of ethnic minorities, was selected to understand how significant the suggested possible causes were in increasing TB incidence. They observed that the increase in TB during the period affected largely the poorest tenth of the Wales and England population living in poor areas. They further explained that socioeconomic factors predominantly accounted for an increase in TB incidence and not race or ethnic minority specific factors, as they observed similar increases of incidence in other ethnic groups. This finding has been corroborated by other studies in London by Mangtani and colleagues (Mangtani, Jolley, Watson, & Rodrigues, 1995); and in Leeds by Goldman and colleagues (Goldman, Teale, Cundall,

& Pearson, 1994) and Cundall and Pearson (1988). These studies have all shown that rates of TB are strongly associated with socioeconomic factors, affecting people living in more deprived areas regardless of their race or ethnicity.

Debate as to whether poverty (socioeconomic factors) or ethnic variables (race) are in themselves the direct cause of high TB rates among migrants or minority groups remains inconclusive and continues in the literature. It is true that living in countries with high TB rates increases the chances of people developing TB infection and TB disease in later stages of life (Morrison et al., 2008). However, as Elender, Bentham, and Langford (1998) rightly put, “variables such as ‘Pakistani’ or ‘Indian’ do not in themselves constitute causal mechanism....within such groupings are a wide variety of genetic backgrounds, cultures, lifestyles and health related behaviours, any of which may contribute to tuberculosis levels” (p. 679).

3.4.2.2 Travels to country of origin

It has been suggested that one risk for acquiring TB among migrants is travel to their countries of origin, where TB rates are higher. It is logical, given the higher rates of TB in their countries of origin, to believe that migrants have a higher risk of TB infection during such travels and are likely to develop TB disease after returning.

Available evidence suggests that long term travellers – travelling for a duration of more than three months – born in low-incidence countries have an increased risk of TB infection (Cobelens et al., 2000). The risk increases with the duration of travel ($p=0.028$) and that the likelihood of acquiring infection is higher for accumulated travel period of more than three months compared to less than three months ($OR=6.0$; 95% CI, 1.2-31.2; $p=0.016$) (Cobelens et al., 2001). Often the risk of infection for long term travellers is of similar levels to the average risk of the country’s population (Cobelens et al., 2000).

Cumulative travel duration of less than three months is associated with similar risks as individuals with no travel to high-incidence countries (Cobelens et al., 2001).

The risk of TB infection associated with migrants travelling to their countries of origin remains inconclusive. The theoretical potential of the risk for migrants remains high as they are more likely to stay longer during their visits and live with family and friends (McCarthy, 1984; Ormerod, Green, & Gray, 2001; Singh, Joshi, & Ormerod, 2006). Studies that have attempted to show this risk in The Netherlands (Kik et al., 2011) and the UK (Ormerod, Green, & Gray, 2001; Singh, Joshi, & Ormerod, 2006) have all relied on regression analysis of patient data, which captures year of diagnosis, year of entry and travel history where available or use of a questionnaire to collect information on travel history (Kik et al., 2011). These studies have the inherent limitation of not showing the conditions of migrants before travel, whether they had TB infection before travel or a compromised immunity before travel. They also do not show when migrants may have become infected with TB, weeks or months after returning or during their visit. This creates a gap in the literature on whether return travels to high-incidence countries by migrants is a risk.

3.4.2.2 Social networks

Social networks refer to the relationship and ties that exist between individuals or groups such as among family, friends or community (Smith & Christakis, 2008). They have both a direct and indirect effect on the health of people. They are important for providing social support through emotional, instrumental, appraisal and/or informational support by serving as the most likely source of information to members of the network and as the source for resources, such as health information, jobs and other opportunities (Smith & Christakis, 2008). They act to influence action of members through social

influence by providing normative guidance and values that shape attitudes of people. Social networks are the main source of social engagements, offering opportunities for people to get together for recreational, religious or other activities. In so doing, they serve as a channel for person-to-person contact, and may be a source of the spread of contagion if a source exists (Berkman, Glass, Brissette, & Seeman, 2000). Thus, social networks can serve as important sources of protection for migrants as well as channels for the spread of infection.

Diagnosis of TB cases or TB outbreaks and subsequent contact tracing or investigation provides information on how social networks of people facilitate or protect people from the spread of TB. Contact tracing helps in identifying close contacts of an infectious TB case who may have developed TB disease or acquired latent TB infection (Ministry of Health, 2010). DNA fingerprinting (genotyping) can also be used to isolate strains that may be identical with the cause of an outbreak (or TB case). Contact tracing or DNA fingerprinting may not show the source of the infection and, by extension, how the disease was contracted; however, it gives an indication of how TB is transmitted among people. Thus, outbreak investigation reports provide a useful way to understand how social networks may facilitate the acquisition and transmission of the TB bacilli.

The relevance of social contacts in TB transmission is illustrated by Hill and Calder (2000), who showed how an outbreak, which initially was believed to have started by a 13 year old girl, spread among a community of Pacific Island church members in Auckland. The church was a close community made up of extended families. Their investigation found that, the likely source case was a 32-year-old woman who would report five months into the outbreak investigation with signs of TB. She was diagnosed with pulmonary TB with further investigation showing she had laryngeal TB. The investigation identified 27 and 57 church/ household contacts with TB disease and TB infection respectively. This supports the hypothesis that the transmission of TB, in

addition to other factors, depends on the closeness and duration of exposure of contacts to an infectious person (Morrison et al., 2008). In this case, the established network of people facilitated the exposure to the contagion.

Social networks of migrants reinforce perceptions about diseases, which may lead to stigma and denial among affected individuals and their network of family and friends within the community (see section 3.4.1.5) (Jenkins, 1966). The investigators confirmed this assertion through the difficulties they encountered in gaining access to the church members for screening, and the insistence of the church pastor not to allow the involvement of Pacific Island health workers because of the shame and stigma.

A similar TB outbreak investigation among a Pacific Island community in Auckland revealed that a mother, the source case, of a seven month old baby, the index case, had been symptomatic for over three months before her diagnosis (Voss et al., 2006). The source case had stayed and provided services as an informal child care attendant for her extended families in multiple households. In the eleven-month period, 24 children were diagnosed with TB disease. The investigators reported challenges of access to contacts for assessment. According to them, anecdotal information obtained suggested that the families involved in the investigation and by extension some families from the particular Pacific Island community had residency issues, financial challenges, and made limited use of health services and other social support services. Reinforcing the earlier submission of how social networks offer opportunities for individuals, in this case a job, and influence behaviour of individuals.

Other outbreaks and contact investigations in North Island, Palmerston North, Auckland and Hawke's bay have demonstrated how TB spread from one person through their networks or contacts to affect several other people (Lester Calder et al., 2000; Calder et al., 2008; De Zoysa, Shoemack, Vaughan, & Vaughan, 2001; McElnay, Thornley, &

Armstrong, 2004). The investigations have shown that, although large numbers of secondary disease or infection are high among close contacts, there are others who have had no close contact with the index case. This confirms the likelihood of tertiary transmission as contacts of the index case who go on to develop the disease and are infectious may continue to transmit the bacilli to their own contacts.

Evidence of interventions aimed at improving TB risk perception among migrants remains low particularly in New Zealand. There is a huge gap in understanding how social networks of migrants affect their perceptions and health seeking behaviour for TB.

3.5 TB Control Strategies

TB remains an important disease for public health and one that continues to engage the attention of governments, policy makers and health practitioners across the world. An important element of this thesis is to review the existing national TB policy documents, focusing on strategies for control of TB among migrants in NZ. In line with this objective and the broader focus of this literature review, the TB control strategies of Australia, Canada, UK and New York city has been selected for review in the ensuing paragraphs to: contextualize TB control efforts in these comparable countries/states; identify strategies or areas of interest and strength that may be transferable; and guide the NZ TB control strategy review and subsequent recommendations.

3.5.2 New York City

The city of New York is a classic example of one that has gone through phases of aggressive TB prevention and control interventions and TB epidemics. In the pre chemotherapy era, the city's department of health proposed and implemented a programme of TB control that had surveillance, follow-up on patients by nurses, public

education and isolation of TB patients as its components (Frieden, Fujiwara, Washko, & Hamburg, 1995). It was a comprehensive programme to fight TB at the time and remains relevant even today.

Over the decades, the incidence of TB disease in New York saw a sharp decline from 14,035 cases representing 246.9 per 100,000 population in 1920 to 2,590 cases (32.8 per 100,000 population) in 1970 (New York City Department of Health, 1993). TB rates had so well declined that, in 1968, a taskforce was commissioned and mandated to develop a plan to eradicate TB from the city (Paolo & Nosanchuk, 2004; Wallace, 2001). The taskforce, based on the assumption of prevailing economic circumstances, proposed a TB prevention and control program that was community based with a gradual phase out of the hospital treatment.

In the 1970s, the fiscal crisis in New York led to a cut in funding for TB control programmes. TB funds plummeted from 1968 through the 1970s to its lowest in 1980, where the amount spent on TB was 80% of the total amount allocated in 1974 (Brudney & Dobkin, 1991). This move was largely due to the erroneous impression that TB had been controlled and therefore the available resources could be focused on other pressing health issues of the time (Paolo & Nosanchuk, 2004).

A series of fire outbreaks in the 1970s resulted in destruction of low-rented houses forcing families and households to abandon homes and communities (Wallace, 2001). There was a rise in overcrowding as families shared homes with relatives and friends, and homelessness sharply increased. Homelessness persisted deep into the 1980s, pushing advocates to force city authorities to construct large shelters to house hundreds of homeless individuals and households (Wallace, 2001). The large shelters presented a perfect condition for the spread of TB from the few existing pockets of individuals with infectious TB. Overcrowding in these shelters and households created the needed

condition for direct, intense and long exposure to the bacilli from people who had TB disease. In addition, stress from the loss of property and loss of social networks influenced the rapid deterioration and progression of TB infection through reactivation to active TB disease among already exposed people (Wallace, 2001).

The epidemic intensified well into the 1990s and peaked in 1992, from 17.2 per 100,000 (1307 cases) in 1978 to 52.0 per 100,000 population (3811 cases) in 1992, after which the incidence of TB steadily declined (Frieden et al., 1995). Frieden and colleagues have suggested that the rapid reduction in TB cases from 1992 could be due to interruption in spread of TB owing to some strategies implemented by the city, including:

Directly observed therapy – according to them, DOTs saw a remarkable improvement with increase in budget allocation resulting in staff increase at the bureau of TB control from 144 in 1988 to over 600 in 1994. The effect was treatment of over 1200 patients by DOT in 1994 compared to less than 50 in 1983, and about 90% of patients completing treatment by 1994 compared to 50% in 1989.

Improvement in measures of infection-control at hospitals; phasing out of large shelters that were housing hundreds of persons in one big room; and improved screening, isolation and follow up of in-mates of correctional facilities may have contributed to reducing TB cases in the city.

These factors, as discussed, might have played a significant role in reducing TB rates in New York City. However, the underlying factors that led to the epidemic were the deterioration of living conditions of people due to rising levels of poverty, overcrowding and the disruption of social networks (Wallace, 2001).

New York City has not eradicated TB yet. In 2014, there were 585 TB cases (7.2 per 100,000 population) of which 84% were among people born outside New York City (New York State Department of Health, 2014). However, previous lessons from this city

can guide present and future TB control interventions. Although complex and difficult to tackle, socioeconomic factors remain important and were the underlying reasons for the New York TB epidemic. Thus, addressing and maintaining high socioeconomic standards and engaging minority communities, as existed prior to 1970s, are key to eliminating TB, even today. As Wallace (2001) rightly puts:

The lesson of the New York epidemic is that the danger lies at home, in the policies of the authorities and majority populations toward minority and marginalized populations. Even native-born citizens who, because of socioeconomic class, religion, or sexual orientation, become marginalized will develop the characteristic clusters of active disease when persecuted, overcrowded, and forced to move from familiar places. Immigrant populations, in and of themselves, form no public health TB threat (p. 524).

3.5.3 Australia

Australia has one of the lowest TB rates in the world. The current rate has plateaued around 4.5 to 5.9 per 100,000 population; a drop from over 45 per 100,000 before the 1950s (The Department of Health Australia, September 2012). The incidence of TB in Australia shows a similar pattern to that of New Zealand, with high cases among indigenous and foreign-born people.

The most recent national strategic plan “The Strategic Plan For Control of Tuberculosis in Australia: 2011-2015” had, as its vision, among others, to eliminate TB in Australia by focusing on: improved treatment and diagnosis; surveillance; eliminating TB among Australian-born persons; and reducing TB among high risk groups (The Department of Health Australia, September 2012). The strategy has identified and pays

special attention to the following: contacts of active cases, the indigenous people and persons born overseas.

Over 80% of TB cases in Australia are due to migrants, with rates showing an increasing trend from 2000 to 2010 (14.1 to 20.4 per 100,000 from 2000 to 2010) (The Department of Health Australia, September 2012). Consequently, the plan has identified two sub-groups within the migrant community for more focused action. One is secondary and tertiary students who migrate from high incidence countries, most of them from Western Pacific region and Southeast Asia region. The strategy, like for most other developed countries, focuses on screening students before entry, and proposes to strengthen the relationship with institutions for screening and early detection of TB. The other important migrant sub-group are health care workers from high incidence countries. TB cases has seen an increase among this sub-group from 17 in 2001 to 83 cases in 2008 (The Department of Health Australia, September 2012). The strategy proposes appropriate screening for healthcare workers from high TB incidence countries and appropriate follow up services when needed.

The strategy, although focusing largely on the biomedical model, has, as one of its objectives, “to maintain awareness and education of all stakeholders, including professionals and local communities of the continuing importance of TB control within Australia”. An indicator for measuring this objective is diagnostic delay, which gives an indication of patient knowledge and risk perception of TB, as well as clinician knowledge and suspicion index for TB. The focus on such an objective may more likely improve early diagnosis and treatment, reducing secondary and tertiary infections and cases, as has been shown from outbreak investigations highlighted in section 3.4.2.2.

A critical element for TB control in Australia is the wide engagement of stakeholders and the diverse roles each may play. The strategic document may be up for

review given the new global plan to eliminate TB and clear focus for direction for low incidence countries.

3.5.3 Canada

In 2014, Canada released a federal framework for TB prevention and control. The goal was to achieve a national TB incidence of 3.6 per 100,000 or lower by year 2015 (The Public Health Agency of Canada, 2014). The strategy has three (3) key focus areas:

To optimize efforts in the control and prevention of TB disease. It prioritises control of the spread of TB disease through early detection of disease, rapid investigation of contacts and treatment of people with disease;

To identify persons with latent TB infection and treat those among them with the highest risk of progression to TB disease; and

To champion collaboration in addressing underlying factors (social determinants) for TB disease.

Like what pertains in New Zealand, the incidence of TB is largely attributed to aboriginal populations and persons born overseas (about 65% of all TB cases) (The Public Health Agency of Canada, 2014). Strategy to control TB among migrants follows a similar pattern of other low incidence countries. Screening for active TB is done for migrants applying from outside the country and for those within the country. Migrants' in-country who are identified as having TB are treated promptly. Migrants applying from outside who show evidence of inactive TB are allowed entry but report to public health officers for follow up after arrival in what is termed the "immigration medical surveillance program".

Among other important elements of the strategy are the key steps being taken by the Public Health Agency of Canada to address major barriers faced by migrants in TB

services. To address barriers of language, culture and others in accessing TB services, the strategy seeks to encourage TB programs to form partnerships with community based programs to provide accessible and culturally appropriate services to migrant populations.

3.5.4 England

The UK government has announced a five year strategy for tuberculosis control in England – “Collaborative tuberculosis strategy for England: 2015 to 2020 (Public Health England & NHS England, 2015). The strategy gives new direction on how TB services would be organised and funded in England. TB remains an important disease in England. In 2013 alone, 7892 cases of TB were reported, representing a rate of 12.3 per 100,000 (Public Health England, 2014): a rate higher than some western European countries, the US, Australia, Canada and New Zealand. People born outside the UK were the most affected by TB representing almost three quarters (73%) of all TB cases (Public Health England, 2014)

The strategy therefore aims to decrease the TB incidence in England yearly, reduce inequalities in TB incidence and ultimately eliminate TB (Public Health England & NHS England, 2015) through a collaboration between public health, social support and clinical care. Ten key areas have been identified for action: access to services; universal access to diagnostics; treatment and care; contact tracing; BCG uptake; drug-resistant TB; TB in underserved populations; systematic implementation of latent TB screening; surveillance and monitoring; and appropriate workforce.

In a bid to strengthen the co-ordination and oversight of TB control activities, the strategy proposed establishment of nine TB control boards along Public Health England (PHE) centre boundaries. The boards, among other things, will be responsible for planning TB control activities, involving underserved populations to address their needs

and reduce inequalities, develop a strategy for workforce and, in collaboration with other non-for-profit organisations, create awareness of TB.

The strategy has identified clear actions to be undertaken to eliminate TB. To improve access and ensure early diagnosis will focus on awareness creation and addressing stigma, especially among high risk groups, and raising awareness of health professionals. Among underserved populations, it proposes to provide integrated management and support, undertake outreach services, provide treatment and support for undocumented migrants and ensure homeless TB patients are provided with accommodation and support during the period of treatment.

The collaborative strategy is an attempt to holistically address TB. It builds on the evidence of New York City and the global plan to eliminate TB. New initiatives, such as the systematic implementation of TB infection screening, are intended to identify and treat persons with TB infection who are at greater risk of progressing to TB disease. These are bold steps, with huge financial implications and one that NZ can learn from. However, it is more skewed towards the biomedical model focusing on treatment to break transmission of TB. Not much attention is given to addressing the underlying social factors that put people at risk of TB. In essence, poverty, overcrowding, stress of integration and other prevailing conditions may still exist putting people at risk of developing TB (Wallace, 2001).

3.6 Summary

The chapter has provided a context of current knowledge about TB among African migrants living in western countries. The literature review showed that there is a paucity of primary research describing the epidemiology of TB among Africans living in Western

countries. The available literature suggests that African migrants have a disproportionately high TB burden per capita compared to the host country born population, are more likely to be diagnosed within the first five years of arrival, and to be HIV positive, which reflects the HIV rates from their countries of origin.

The critical review identified and discussed some gaps in the literature including: few studies describing demographic characteristics and risk factors associated with TB among African migrants and; no published study describing the TB epidemiology, migration patterns and geographic origins, and locations of African migrants living in NZ.

The chapter further discussed the current literature on the determinants of TB. It demonstrated that, at the individual level, general TB awareness among African migrants could be high, however, the biomedical understanding of TB may vary. The review also revealed that the decision by African migrants to seek early treatment for TB did not only depend on their knowledge level, but was largely influenced by the economic, social and health system factors, which were beyond their immediate control. Some gaps in the literature on TB determinants included: very few published articles exploring the socio-cultural meanings and risk perception of African migrants within the context of their transitioning into new environments; very little research on stigma; very few published works exploring work life or life after TB treatment; and no published articles exploring the determinants of TB among African migrants in NZ.

TB control strategies of comparable countries were also reviewed in this chapter. Adequate and sustained funding, including active engagement of most at risk groups in the planning and implementation of interventions, were considered key strategies for TB control. The dominance of the biomedical approach was further discussed.

The next chapter describes the methods employed in this study. It begins with a description of the conceptual framework guiding the study. The choice of study methods, participants and the interview questions guide, all of which draw on the findings from the review, are discussed.

Chapter Four – Method

4.0 Introduction

The preceding chapter contextualised current knowledge on TB among African migrants living in western countries. This chapter builds on what is already known by discussing the approaches used in conducting this study and justifies why these approaches were chosen. The chapter begins with a discussion of the conceptual framework for the study, followed by a discussion of critical realism, the philosophical underpinning of the study; mixed method approaches; sequential explanatory mixed method research design; and a detailed presentation of the two phases of the study.

4.1 The Conceptual Framework

There is renewed support for public health action to refocus on the wider determinants of health (Marmot, 2005; Marmot, Friel, Bell, Houweling, & Taylor, 2008). The WHO Commission on Social Determinants of Health (CSDH), which was established in 2005 with the mandate to support countries in addressing the underlying factors of ill health, has defined social determinants as the conditions in which people are born, grow, work, live, age and the wider forces that influence the distribution of power, money and resources that shape conditions of daily life (CSDH, 2008). The commission has argued that improved health lies beyond the usual remit of the health care system.

In their seminal paper describing policy directions and approaches to addressing the social determinants of health, Solar and Irwin (2010) has suggested that health as a social phenomenon requires complex multi-sectoral policy actions and interventions to tackle the underlying social mechanisms that produce health inequities among different population groups. They argue that addressing “the social determinants of health

inequities is a political process that engages both the agency of disadvantaged communities and the responsibility of the state” (Solar & Irwin, 2010 p. 22). Hence, to achieve public health goals, countries must seek to act on the underlying causes of ill health, ‘the causes of the causes’, by actively engaging and changing the distribution of power (empowerment) that benefits the disadvantaged and vulnerable groups in society.

The evidence, as discussed in the preceding literature review, suggests that most cases of TB among African migrants are likely due to reactivation of previously acquired infections prior to migration to NZ. The wider determinants of health, as emphasised by the CSDH above, are important in influencing ill health. In the case of TB, these factors may contribute to an individual’s risks to TB infection and subsequent progression to disease. In this section, a conceptual framework, the African Hut Model, is proposed that offers an accurate explanation of the observed phenomenon. The framework evolved from a similar model proposed by Neave (2013) with respect to imported malaria.

The framework draws on the socio ecological perspective of health. The socio ecological perspective of health is a theoretical framework to understand the dynamic reciprocal interactions that exist between the personal and wider environmental factors (social and physical) in determining observed health patterns (McLeroy, Bibeau, Steckler, & Glanz, 1988). In extending the nested model of Bronffebrenner (Bronfenbrenner, 1977), McLeroy and colleagues (1988) suggested five levels of mechanisms that interact to determine health behaviour or patterns. These are the intrapersonal, interpersonal, institutional, community factors and public policy. The first level, intrapersonal, refers to individual factors such as knowledge, attitudes, beliefs, and biological factors that interact to influence predisposition of an individual to a health condition. The interpersonal, the second level, denotes the interaction that exists within families, friends, work groups, other social networks and the support derived from these significant others, which influence health behaviour. The third are the institutional factors, which relate to how

established institutions or organisation characteristics and processes influence individual behaviour. The community factors describe the interactions that exist at the aggregate level of the organisations/ institutions, and the interpersonal levels, which shape larger community norms and individual behaviour. The fifth factor, public policy, influences resources allocation and accessibility to health and other social services. The ecological perspective was most appropriate for this study as I sought to identify and explain the most relevant factors with the potential to influence the incidence of TB disease among African migrants. Such an approach has the benefit of understanding health problems in a holistic manner (McLeroy et al., 1988; Stokols, 1996).

Humans exist as complex entities shaped by their environment. Hence, an attempt to explain human behaviour exclusively from a single perspective undermines the complex and dynamic interactions that exist between the personal attributes (such as genetic), environment and other significant situational factors that shape individual behaviour (Cohen, Scribner, & Farley, 2000; Stokols, 1992). Behaviour or lifestyle theories – theories that explain individual health related decision making and behaviour – ignore the connection between individual actions and the social norms, values and expectations, which are often a creation of the wider social environment. Behavioural theories further discount the impact of the environment, the built and natural, on individual behaviour (Glass & McAtee, 2006; Sallis et al., 2006). Whilst it can be argued that the individual has the ultimate responsibility to improve their own health (Weinstein & Rothman, 2005), an overemphasis on behaviour change could lead to ‘victim blaming’ people who are unable to adopt the expected healthy lifestyles, and have been shown to make modest achievement (Fisher et al., 2005; Glanz, Sallis, Saelens, & Frank, 2005; McLeroy et al., 1988; Stokols, 1996).

One key limitation of an ecological approach, however, is the lack of specific variables in conceptualizing appropriate constructs that explain an identified health issue

(McLeroy et al., 1988). The multiplicity of variables at each level of the socio ecological model makes it difficult to discern how specific factors might interact across the different levels to produce observed health patterns, which can lead to inadequately specific interventions to address the health problem. Whilst the lack of specific variables is a weakness of the model, it also demonstrates its flexibility and wide application to guide the development of operational models for public health promotion actions (McLeroy et al., 1988). In addressing this inherent weakness of lack of specific variables, I adopted three key factors - the social, economic and structural - that were identified from the existing literature to be important determinants of TB. These factors contribute to shaping healthcare access, exposure to TB, unhealthy behaviour among others, as explained by Lonnroth and his colleagues in their framework for proximate risk factors and upstream determinants of TB (Lönnroth et al., 2009). The framework also included the contextual factors (structural, social and physical environment) within the source countries of migrants, which have been shown by Neave in her doctoral thesis as important in influencing health behaviour in the host countries (Neave, 2013). This framework does not only show the interactions between factors, but importantly, the need for interventions across the factors concurrently to eliminate TB among this population sub-group.

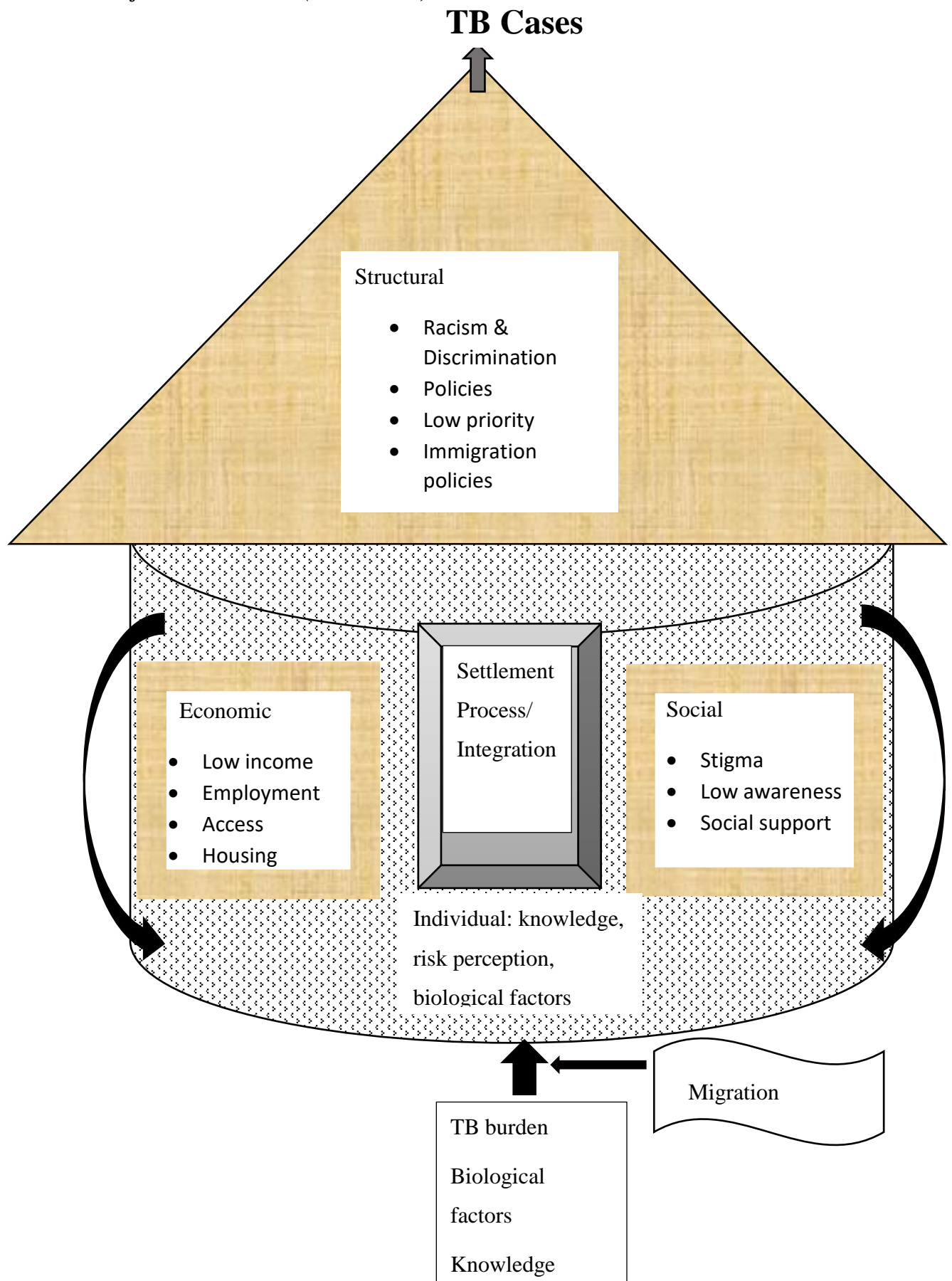
The framework, depicted by a traditional African hut has a round base, two windows, a door and a roof, and is being used metaphorically to explain the key determinants of TB among African migrants in NZ. The rectangular shape at the base of the framework, outside the hut, captures the living circumstances of Africans in their countries of origin before migration. These include the burden of TB, biological factors (other diseases, weak immune systems, previous exposure, age), their knowledge on TB and perceptions based on their lived experiences. The migration process is indicated in the framework to emphasise the effect it could have on an individual's vulnerabilities to TB. The journey people embark on to flee emergencies and/ or their transits in camps

during the process could place them under extremely stressful conditions and may include months to years of living in crowded, poor and under difficult conditions (Dhavan et al., 2017). The process of integration or settlement in the new country is depicted as the door of the hut. The door is used metaphorically to represent a port of entry into their new spaces and new opportunities as well as challenges. The process through which new Africans get settled in their new environment has been shown in the results chapter of this thesis to be fraught with challenges, which has the potential to significantly impact their health and wellbeing. The hut has two windows, representing the economic and social factors. The windows symbolise an opening through which these two factors in the new society might interact dynamically to impact the individual living in this hut. The roof of the hut metaphorically represents the protection for migrants from the harsh conditions of their new environment and depicts the structural factors such as racism and discrimination, and policies that influence an individual's access to TB care. Finally, inside the hut is the individual whose risk to TB is an interplay of their knowledge on TB, other biological factors and the four key determinants discussed above.

Details of this framework and how it could be utilized will be discussed further in the final chapters of the thesis. See figure 4.1

Figure 4.1

The African Hut Model (Framework)



4.2 Epistemology

Epistemology generally refers to the study of knowledge, its creation and dissemination, in an area of inquiry (Creswell, 2014; Crotty, 1998). It is concerned with what we know, how we acquire that knowledge, the limits of what we know and how we justify what we know (Crotty, 1998). The study is framed within a critical realist perspective (Bhaskar, 1975). This approach postulates that what we consider reality and knowledge consists of two facets. It is both a social product and, just as any product, its production depends on how it is produced and who produces it; and the part that is not produced by human activity exists independent of us knowing of it (Bhaskar, 1975). These two aspects are often referred to as transitive and intransitive, respectively. The intransitive objects of knowledge exist as an independent reality, which may be unknown to us, may not be spoken of, and would continue to exist until studies can produce knowledge of such objects. As Bhaskar (1975) puts it

The intransitive objects of knowledge are in general invariant to our knowledge of them: they are the real things and structures, mechanisms and processes, events and possibilities of the world; and for the most part they are quite independent of us. They are not unknowable, because as a matter of fact quite a bit is known about them. But neither are they in any way dependent on our knowledge, let alone perception of them. They are the....objects of scientific discovery and investigation (p. 22).

This philosophical stance towards knowledge production accepts that our understanding of the world can never be truly objective, rather all knowledge is considered fallible and incomplete, allowing the possibility of varied accounts of observed phenomena in the world (Maxwell & Mittapalli, 2010).

4.2.1 The Generation of Knowledge

Critical realists argue that the world around us is stratified into three domains; the real, the actual and the empirical. The domain of the real refers to what exists, natural or social and their structures and associated power relations, independent of our knowledge, thoughts or impressions of their existence (Sayer, 2000). This domain of the real is typically the focus of enquiry, to explain how these structures and powers interact to generate mechanisms or observed world patterns. In terms of this project, the focus was to explain how varied dimensions (individual, economic, social, and structural) interact to produce relatively high TB rates among African migrants. The second domain, the actual domain, is what happens when the structures and their powers in the real are activated to generate events. This domain is distinct and happens independently of our experiences, whether we experience them or not (Houston, 2001; Sayer, 2000). The empirical domain, the third of the domains, consists of all the experienced events that are products of the social world.

In the social world, critical realists argue that the society is an open system, one made of individuals who effect it (form it) and are affected by it (House, 1991). The social world is seen as stratified and people have powers and properties that endow them with thoughts and creativity about the varied social context they confront (Archer, 1998). In such open systems that have the capacity to change, any enquiry therefore seeks to apply antecedent knowledge using theory or models to explain, predict or diagnose observed patterns of phenomena or mechanisms that generate the events of the actual world (Bhaskar, 1975). Critical realism provides a useful philosophy due to its acknowledgement of the real domain and the socially produced structures that impact it, which made it useful for this study to explain how social structures impact personal factors or realities in determining incidence of TB among African migrants.

Critical realism supports the legitimacy of the mind (mental) and the physical context in making sense of the events that make up the experience or reality of people. Thus, reasons, intentions or beliefs are real events that may lead to action, observed in the physical, whilst the physical and social context can influence the beliefs, intent and perspectives of individuals. To a critical realist, “not only are individuals’ perspectives and their situations both real phenomena, but they are separate phenomena that causally interact with one another” (Maxwell and Mittapalli, 2010 p. 157). This philosophical stance offers a suitable framework for understanding the actual situation that individuals are faced with, their own perspective on such and to explain the relationship between the actual events and the individual perspectives. Thus far, personal beliefs, attitudes and practices are real events that are equally important to be known through the process of knowledge generation, to explain how they are shaped by other social structures and how they, in return, shape them.

The purpose of research to many critical realists is one that is political as it seeks to understand how existing structures interact to create inequalities. The facts (inequalities) derived from the findings in turn are used to develop value arguments against prevailing inequalities or wrongs of society (Cruickshank, 2003). This perspective offers the opportunity to assess a social system from within (inside) by identifying potential factors that can lead to desired changes or transformation of the system and not by simply putting forward or enforcing one perspective (Bhaskar, 1998). Taking into consideration the broader social, cultural, economic and health system factors and the philosophical framework underpinning this study, opinions from African migrants themselves, the people affected, was sought and the findings used to develop value arguments to propose recommendations that may serve as advocacy tools in developing control strategies for TB in NZ for African migrant communities.

In line with Bhaskar's (1975) assertion of research as "the production of knowledge of those enduring and continually active mechanisms of nature that produce the phenomena of our world" (p. 47), this study sought to explain the observed patterns of TB cases among African migrants as the object of study using existing understanding and definition among the African communities in Auckland region; and sought to produce knowledge on the complexity of the interacting mechanisms, structures or tendencies generating the observed trends. The outcome of this study is in accordance with the critical realist model of explanation, that is, the framework (mechanism) proposed after the study is capable of explaining the observed trend, and that there is evidence to support its existence (Outhwaite, 1998).

Critical realism is compatible with various research methods, whether used alone or together depending on what an enquiry seeks to achieve. Choice of study methods is thus contingent on the objectives (object) of study. As affirmed by Sayer (2000), "most importantly, realists reject cookbook prescriptions of method which allow one to ignore that one can do research by simply applying them without having a scholarly knowledge of the object of study in question" (p. 14). For this project, a mixed methodological approach was adopted to fully explore the study objectives.

4.3 The Mixed Method Approach

Mixed method approaches are increasingly becoming popular given their suitability for applied research (Creswell, 2014; Johnson, Onwuegbuzie & Turner, 2007). This research approach encompasses multiple methods from the two main methodologies, quantitative and qualitative, and was born out of the desire of researchers who perceived both quantitative and qualitative methods as useful together in addressing their research questions (Creswell, 2014).

Mixed method does not only involve a combination of the two research methods in one study but can include the use of different data types, methods of analysis and for different population groups using different quantitative or qualitative methods alone or together in one study (Morse, 2010). The mixed method approach taken is shaped by the research question of the study. This approach has several strengths associated with its use, making it useful for researchers and health practitioners (Creswell, 2014). Bryman (2008) has listed some of these strengths as: for purposes of triangulation to improve on the validity of study findings; provides potential to maximise the strengths of both research approaches synergistically; capable of answering different research questions in one study; capable of explaining observed trends with each finding complementing the other; and has the potential to provide findings that are likely to be more useful for practitioners and policy makers owing to its applied focus and potential to address complex social issues.

Public health issues are complex and diverse, and can require multiple study methods to explain them. Qualitative and quantitative methods in themselves, alone, can be useful but might be inadequate in addressing such complexities (Hesse-Biber, 2015). Qualitative methods are flexible and focuses on generating descriptions and explanations for observed phenomena (Hammersley, 2013). These methods emphasise in-depth understanding of complexities by subjectively exploring the perceptions of the study participants, which would be used to support a model to explain the determinants of TB. Quantitative methods, conversely, allow for large samples of the target group (as in this thesis the five-year national TB data) to be studied and emphasises the generalizability of results across other members of the target group (Crotty, 1998; Hammersley, 2013). However, to use either of these methods to study such a complex health issue like TB could lead to a narrow focus on the different aspects of the health problem rather than to

provide a holistic understanding of it (Creswell, 2009). Employing a mixed method approach, although time consuming, could help to answer the broader questions around TB and to further present deeper insights than either of the two methods would (Creswell & Plano Clark, 2011).

4.3.1 Selecting the type of mixed method design

Debate in literature persists over the types of mixed method designs as there are potentially limitless possibilities for combinations (Creswell & Plano Clark, 2011; Morse, 2010). The most common, however, are the convergent parallel, sequential (explanatory or exploratory), embedded and multiphase designs (Creswell & Plano Clark, 2011). Convergent designs implement quantitative and qualitative strands concurrently and mix the two in the interpretation of the study findings. In embedded designs, researchers add a supplemental strand such as a qualitative strand to the main traditional quantitative study and vice versa to enhance the original study design. Multiphase designs involve a combination of convergent and sequential design elements usually over a period in a multiple study that may have a common purpose. Sequential (explanatory or exploratory) designs, on the other hand, are largely used to study a phenomenon in phases where the results of the initial phase is used to inform the second phase of the same study. The main aim of sequential designs is to explain in depth the mechanisms that shape the results from the quantitative analysis (as in sequential explanatory designs) or that the quantitative study is used after the analysis of the qualitative findings to ascertain whether the results from the initial study can be generalized (as in sequential exploratory designs) (Ivankova, Creswell, & Stick, 2006). The wide range of options for mixed method designs means TB among Africans could be approached in various ways. The choice of one design over the others is not necessarily because of its superior qualities, but the design's suitability for the study, its objectives and research questions.

4.3.2 The Sequential Explanatory Mixed Method

For this thesis, the sequential explanatory mixed method approach was adopted as the study sought to produce new knowledge by following a process of staggered information gathering and interpretation (Creswell, 2014; Greene, Caracelli, & Graham, 1989; Ivankova et al., 2006). The rationale for sequential explanatory design is to use the quantitative data and analysis (in phase I) to provide a general understanding of the topic of inquiry. The second phase, the qualitative data collection and analysis, explains the results from the quantitative analysis by exploring, in depth, the perspectives of participants (Creswell & Plano Clark, 2011; Ivankova et al., 2006; Morse, 2010; Morse & Niehaus, 2016). This approach was considered the most appropriate to answer the research questions due to its potential to explain an observed phenomenon using different research methods with one preceding the other and each contributing to the understating of the phenomenon as the qualitative results was intended to help in explaining the quantitative (TB surveillance) analysis results (Creswell, 2009).

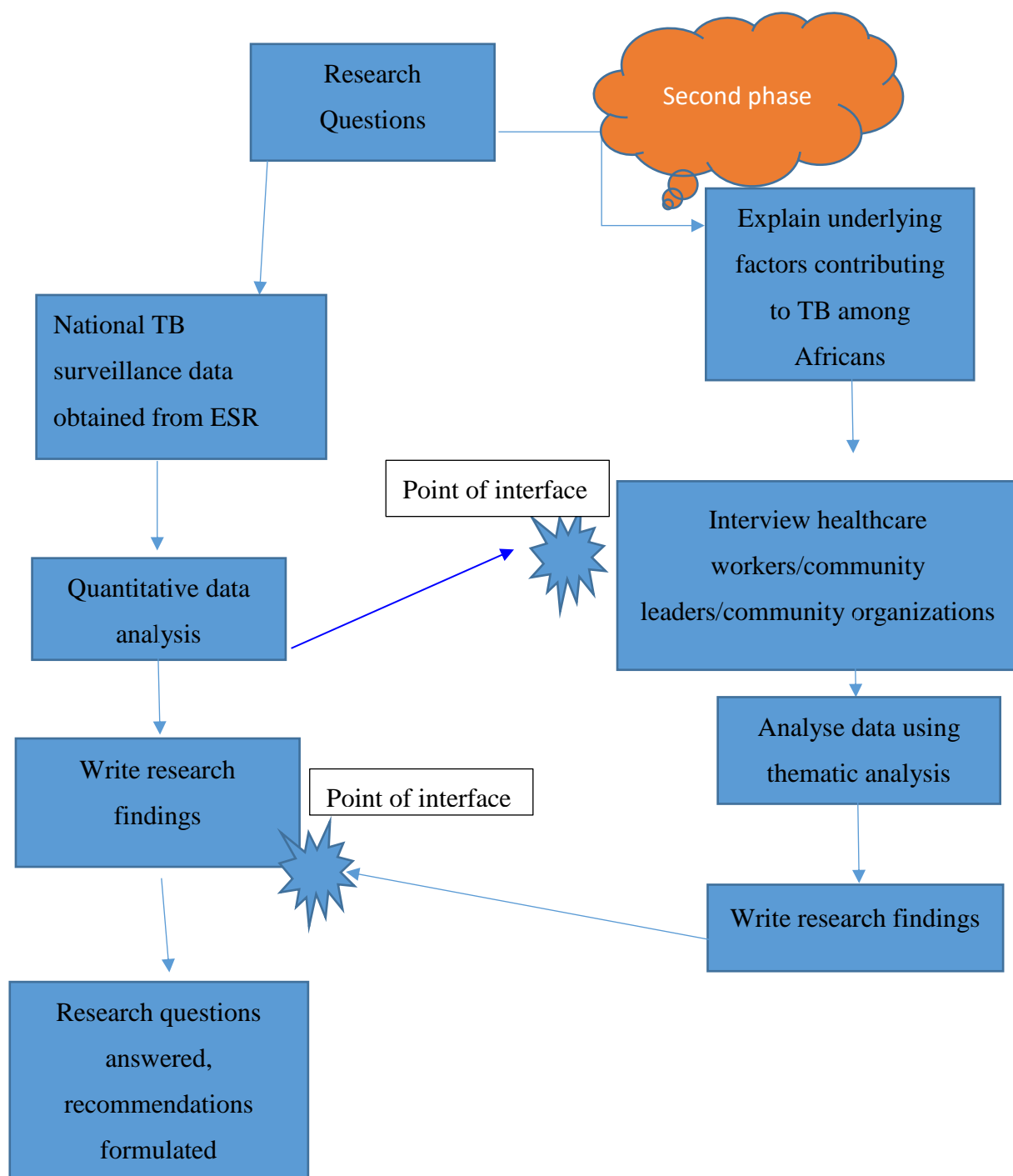
The sequential explanatory mixed method strategy adopted in this project involved two phases. The first phase was a quantitative study and involved an analysis of a five-year (2010-2014) national TB surveillance data obtained from The Institute of Environmental Science and Research (ESR), and grey data from the national annual TB reports. The analysis provided information on the trend of cases among the target group over the five-year period and established background epidemiological information, in relation to key demographic variables, risk factors, incidence, and the geographical patterns of TB disease among the target population. The second phase involved a qualitative research and sought to explain and understand the mechanisms (social, individual, structural) that interact to produce observed patterns identified in the quantitative analysis. Here, data was gathered via semi-structured interviews with health

care workers, a worker from a charity organization providing support for persons with TB and African community leaders living in Auckland. A diagrammatic representation of the mixed method design is provided in line with best practice (Morse, 2010) (see figure 4.2).

The point of interface, which refers to where the two separate studies were mixed, was at the data collection stage of the qualitative study and at the presentation of the analysis of the results section. Recruitment was informed by the demographic characteristics, from the results of the quantitative analysis, to purposively sample study participants. Likewise, the design of the interview question guide was shaped by findings from the quantitative analysis to further explore participants' perception of the possible explanation of the observed results. Key questions on specific risk variables identified from the quantitative data analysis formed part of the interview guide. Finally, the point of interface for the two results was at the discussion of the results section, where findings from the quantitative analysis was used to contribute in the narrative reporting and discussion of the qualitative data.

Figure 4.2

Diagrammatic Representation of the Mixed Methods Research Approach



4.3.3 Ethics Approval

Ethical approval was sought from the institutional (Auckland University of Technology) ethics review committee (**reference 16/128**). The study further received an out of scope letter from the NZ health and disability ethics committee (HDEC) – a ministerial committee that functions to ensure all research meets ethical standards – confirming that it involved a minimal risk to participants. In addition, an institutional approval (**A+ 7254**) from the Auckland district health board research review committee was sought (See appendix A).

The ethical considerations for studies involving human participants include: informed and voluntary consent of study participants; respect for participants' privacy and confidentiality; minimisation of risk to researcher and participants; respect for the vulnerability of some study participants; and the limitation of deception of the participants. Of particular relevance to this study were: informed and voluntary consent; privacy and confidentiality; and the minimisation of risk.

To maintain confidentiality, all data retrieved from the national TB surveillance data through ESR were anonymised. In addition, security measures in relation to safe storage and access to the obtained data were ensured to minimise the loss of data and other security concerns. Only persons who had signed the confidentiality agreement form with ESR had access to the TB data.

The researcher was aware of his role as an interviewer and the potential harm (including stress, embarrassment, emotional distress, stigma, disclosure of confidential information and fatigue) the interview process could present to study participants through the art of listening, questioning and probing. Accordingly, steps were taken to minimise harm to study participants. At the recruitment phase, persons who agreed to participate in the study were adequately informed of the research intent and level of participation. A

detailed form that provided information on the study (See appendix B) was given and written consent (See appendix C) obtained before the start of each interview.

In the light of the sensitive nature of the topic, verbal consent of participants was sought intermittently during the interview to allow participants the choice to continue or disengage from the study at any time when they felt uncomfortable or wanted to reconsider their participation.

Efforts were also made to minimise unintended harm resulting from the questions to study participants. The study had planned to offer participants professional psychological support by referring them for the needed support where necessary in the unfortunate event that the unexpected happened. However, none of the participants looked visibly distressed or mentioned throughout the interviews that they needed any form of professional help.

Throughout the data collection process, anonymity of participants was maintained. Unique codes were used as identifiers for participants in data capture, transcription and writing up of the research findings. Strict adherence to maintaining confidentiality such as safe handling of audio tapes of interviews, transcripts and field notes, was employed. In doing so, participants were constantly assured of non-disclosure of their statements to other persons without their explicit authorisation.

4.4 The Research Design

The research was conducted in two phases. Phase one of the study involved the quantitative analysis of surveillance data while the second was a qualitative study. A detailed description of each phase is presented in the sections that follow.

4.4.1 Quantitative Research Methods (Phase I)

This section describes the quantitative research methods used in the first phase of the study. This phase comprised of a descriptive epidemiological analysis of TB surveillance data of all cases of TB reported from 2010 to 2014. The variables for the analysis were selected based on the literature and their comprehensiveness in describing the epidemiology of TB by time, place and person in line with the research question. The aggregate notification data were reviewed, the variables extracted from the data set, aggregated and analysed. The purpose for analysing the TB surveillance data was to identify population characteristics of persons diagnosed with TB and the likely factors that predispose people to TB in NZ.

Secondary analysis of already existing data presented an opportunity to reduce time, a critical constraint for research, as was the case of this study. Analysing secondary data also reduces the burden on respondents as they are not required to fill out questionnaires. For the researcher, it eliminates the need to recruit participants, which might be fraught with challenges of biases in the responses provided and the actual numbers of people who offer to fill them (Bryman, 2008). Whilst secondary data may have some limitations, such as sampling, the TB surveillance data captured the information of all reported TB cases (required by law) in the EpiSurv national database. Thus, it was the best dataset available.

4.4.1.0 Methods for Exploring Epidemiology of TB

4.4.1.1 Data source of numerator

Any clinician who diagnoses TB disease is required under the Tuberculosis Act 1948 to notify the local Medical Officer of Health. In addition, since 2007, laboratories are required to report TB cases to their Medical Officer of Health. The laboratory report

provides details on drug susceptibility and species identification of notified cases. The TB case report form (see appendix D) captures details on case demography, clinical, laboratory, risk factors and case management, which are entered into EpiSurv by staff at public health units (Institute of Environmental Science and Research Ltd (ESR), 2015). In the analysis, cases classified as confirmed (defined as cases that are laboratory confirmed) or probable (defined as presumptive cases with no laboratory confirmation but with symptoms compatible with TB including radiology or clinical evidence and a full course of treatment is started) and notified from first January 2010 to 31st December 2014 were used (Ministry of Health, 2012). The inclusion of both confirmed and probable cases (clinical diagnosis or radiologic examination) in the analysis is necessary because laboratory confirmation of TB is not always possible. For instance, in some cases when TB affects intrathoracic lymph nodes and children, obtaining a sample for analysis can be difficult (Antoine & Abubakar, 2013).

All notified TB cases born in a sub-Saharan African country were classified as “African” for this study and used as the numerator to analyse disease rates. Cases born in NZ were aggregated as the “NZ born”, whereas, all cases born outside NZ but not in any sub-Saharan African country were aggregated and used as the numerator in the analysis as “other foreign born”.

4.4.1.2 Data source for denominator

4.4.1.2.1 Census data

The census provides the largest dataset of detailed information about a country’s population. It is extensively used by national and local governments for allocation of resources and for academic research as a denominator in calculating rates. In NZ, census is conducted every five years to count the number of people living in the country on the census night.

Census data, however, are not flawless; they tend to over count (count population more than once) or undercount (miss people). Smaller ethnic communities and new migrants are among the group more likely to be undercounted (Statistics New Zealand, 2014). To adjust for undercounts and over counts, post-enumeration surveys (PES) are conducted to improve the quality and accuracy of the post censal population estimates (Statistics New Zealand, 2014). The 2013 PES results showed that 97.6% (about 103,800 people were not counted) of resident population in New Zealand were counted on census night with variations in coverage for different population groups. For instance, a comparison of the priority ethnicities showed highest net undercounts among Māori (6.1%), followed by Pacific (4.8%) and Asian (3.0), and the least among European (1.9%).

Also, population estimates calculated several years after a census may not give an accurate reflection of population trends in a country, as populations and settlement patterns tend to change, sometimes more rapidly, in between census times, meaning projections from previous census may not reflect actual trends in the years ahead. Hence, the use of estimates may not provide an accurate representation of the population at a point in time. The two variables captured in the census data that were necessary as denominators to estimate TB rates were ethnicity and birth place.

4.4.1.2.2 Ethnicity data issues

The current study identified issues related to the use of ethnicity data as the denominator, particularly for Africans in NZ. The issues derived from the ethnicity data collection and classification of responses into categories. Ethnicity, as defined by Statistics New Zealand,

- *a common proper name*
- *one or more elements of common culture, which need not be specified, but may include religion, customs, or language*
- *unique community of interests, feelings and actions*
- *a shared sense of common origins or ancestry, and*
- *a common geographic origin.* (Statistics New Zealand, 2005).

Figure 4.3
New Zealand Census Standard Ethnicity Question (source Statistics NZ 2013 Census Questionnaire)

[illegible]

The ethnicity question does not include ‘African’ ethnicity in the list of available options for respondents to select. Hence, persons who identified as Africans or by their country of birth had to mark ‘Other’, and needed to state their ethnicity or country of origin in the space provided. To provide a response for the ‘Other’ ethnicity would require the ability of the respondent to write or enter text. It could be the case that not all persons who identified as Africans would complete this.

After respondents have specified their ethnicity, the data are recorded and classified. In NZ, ethnicity data is classified according to the Ethnicity NZ Standard Classification 2005 (ETHNIC05), which classifies ethnicity into four hierarchical levels. Level one is the top most category with least detail and have six codes including: 1. European, 2. Māori, 3. Pacific Peoples, 4. Asian, 5. Middle Eastern/Latin American/African and 6. Other ethnicity. Level two has 27 codes while level three has 42 codes. Level four has the most detail with 239 codes and captures the closest of what people state on the form.

Although ethnicity must be self-identified, as stated in the definition, the classification system that is used to group responses into meaningful categories are not self-identifying. The classification structure, which aggregates ethnicity into broader ethnic groups according to geographical origin or location, or cultural affiliation, might not necessarily align with individuals self-identified ethnicities (Ministry of Health, 2016). For instance, it is the case that individuals who stated/wrote ‘South African’ or ‘Zimbabwean’ as their ethnicity would be classified at level three as ‘Other European’ and level one as ‘European’. This would include individuals who would have preferred to identify as belonging to the African ethnicity. Again, persons who stated, ‘South African Coloured’, ‘Mauritian’ or ‘Seychellois’ were classified as ‘Other ethnicity’. Whereas others who stated, ‘United States Creole’, ‘Jamaican’, ‘African American’ and

‘West Indian’ were categorised at level 3 as African and level 1 as MELAA (Statistics New Zealand, 2005). These categorisation system raises concerns about the use of the ethnicity data. This study contends that the African ethnicity is under-reported in the census and its use as a denominator may not give a true reflection of the size of the population.

4.4.1.2.3 Place of birth

The place of birth data, which captures the country of origin of respondents, was considered most appropriate for the analysis. Although this might not represent the African ethnicity, using the country of birth as the denominator and notified TB cases by country of birth as the numerator would provide an estimate of TB rates that reflect persons born in Africa and help to understand the associated risks for the population group. Persons born in sub-Saharan Africa may have be at risk of TB because of the disproportionately high burden of TB in the region.

The official end of June mid-year population estimates available from the Statistics NZ website were used as the denominator in the analysis of the national TB rates. With the national population changing at different times in a year because of births, deaths and emigration/migration, the mid-year population estimates offer a sufficient approximation of the national population (close to the mean population) in a year. The estimated usual resident population by country/ place of birth was used as the denominator for the analysis of specific rates for the three compared population groups, African, Other foreign, and NZ born. The African population was estimated by applying the estimated proportion of sub-Saharan Africans by country of birth from the 2013 census to the end of June usual resident population estimates from 2010 to 2014 published

on the official website of statistics NZ. The population estimate was used as the denominator in analysis of African specific variables.

4.4.1.3 Method of epidemiological analysis

The epidemiological analysis was carried out using R statistical tool version 3.3.1 and MS Excel. The analysis assessed the distribution of TB notification rates per 100,000 population at national level, sub-national areas (District health boards), and among the different population groups such as age, sex, and birth place. Summary measures such as crude incidence rates, proportions and percent change in incidence of TB cases for each year within the period under review were calculated. Crude, age and sex specific incidence rates for the target population were compared to other population groups within the specified time frame. Chi-square test was performed to assess statistical significance of the association between categorical variables, and all confidence intervals were calculated at 95%. Simple linear regression analysis was conducted to assess trends in TB rates over the study period at 95% confidence interval.

4.4.1.3.1 Population disease rates

The crude incidence rate for each year, 2010 to 2014, was calculated by dividing the total TB cases notified in each year by the June end population estimate and multiplying by 100,000: 95% confidence interval was calculated for each year's notification rate using the formula:

$$95\% \text{ upper limit} = \left(\frac{100000}{n} \right) \left(d + (1.96 \times \sqrt{d}) \right)$$

$$95\% \text{ lower limit} = \left(\frac{100000}{n} \right) \left(d - (1.96 \times \sqrt{d}) \right)$$

(Where d= number of cases notified from which the rate is calculated, and n = the sample size).

Due to the significant decline in recent times in the number of deaths from TB disease, especially in most low incidence countries including NZ, mortality rate may not be as good an indicator for this study as compared to morbidity data (Antoine & Abubakar, 2013). Notwithstanding, proportions of cases that died were calculated and compared between the three population groupings adopted in this study.

4.4.1.3.2 Notifications by time

Notifications and notification rates were calculated for each year for the five-year period, 2010 to 2014, to demonstrate trends in rates over time. A simple linear regression at 95% confidence was done to assess in between year change in notifications and rates. An analysis of the length of time from arrival to notification of TB was undertaken (post-arrival time) for all foreign-born TB cases for each year, using the variables 'report date' and 'arrival date'. A chi-square test was conducted to compare the difference in the length of time from arrival to notification for all other cases born outside NZ and that of African immigrants. The interpretation of the findings from the different time frames factored in TB control measures, disease outbreaks and the patterns of migration by persons from Africa into NZ within the specific period (Perilla & Zell, 2012).

4.4.1.3.3 Notifications by age

To describe the distribution of TB among the different age groups and to show variations in notifications, an analysis was conducted for the different age groups using the age group variable as used in the aggregate TB surveillance data in EpiSurv as the numerator data and the age group specific June end population estimate as the denominator multiplied by 100,000. The trend of cases by year among the different age groups within the entire NZ population, the two population groups and African migrant population is shown. Among African cases, particular attention was paid to cases among

children less than 15 years, which better reflects continuous recent transmission of the disease within the target community (Antoine & Abubakar, 2013).

4.4.1.3.4 Notification by sex

An analysis of aggregate TB cases to show the trend of TB distribution among males and females over the five-year period was conducted using the sex variable as the numerator and sex specific population estimates at the national level, by age group and by the different population groups compared, as the denominator.

4.4.1.3.5 Mode of discovery of TB

All cases were analysed to show a trend in the differences of discovery or detection of TB disease. The mode of discovery variable was used and proportions calculated for each mode of detection for the national population and African migrants.

4.4.1.3.6 Outbreak cases

The total number of outbreak cases – defined as two or more TB cases known to be linked by epidemiological investigation or DNA fingerprinting (Ministry of Health, 2010) – over the study period were analysed by age groups to show the variations in proportions of cases among the different age brackets, and by the three population groups compared.

4.4.1.3.7 Pulmonary TB

An analysis of all pulmonary TB cases by year and place of birth was carried out using the pulmonary disease variable. Proportions were calculated for each year and for the three population groups. The time interval between the onset of symptoms and start of treatment for all pulmonary TB cases was calculated.

4.4.1.3.8 Notification by occupation

The occupation variable was used in the analysis to show the notification of TB by the different types of occupation among African migrants. All occupations were classified using the Australian and New Zealand standard classification of occupations (ANZSCO) level two. The choice of ANZSCO level two was to provide a broad categorisation with adequate differentiation within categories compared to the level one, which offers very broad categorisations with little differentiation within categories. The analysis then focused on five occupations from the ANSCO broad categorisation, which were classified as priority occupations for this study based on the literature. The proportion of TB cases from each classification was calculated for the African population over the study period.

4.4.1.3.9 Notification by deprivation

The NZDep2013 index, a measure of relative deprivation of the meshblocks (small areas of at least 100 people) in NZ, was used in the analysis to assess variations in proportions of notified cases between the least and most deprived small areas. The NZDep2013 provides a score for the small areas based on a combination of nine deprivation variables, household income, communication, employment, single parent families, qualifications, home ownership, access to car, housing occupancy, and means tested benefits (Atkinson, Salmond, & Crampton, 2014). The index divides the country into tenths (deciles) with the scale of one representing the least deprived 10% and 10 representing the most deprived 10% of the small areas in NZ. The NZDep2013 can also be displayed in quintiles, as in this analysis, where quintile one represents the least deprived 20% and quintile five represents the most deprived 20% of small areas in NZ.

4.4.1.3.10 Notifications by geographical location

To assess the burden of TB by place, a district health board (DHB) variable was used as the numerator, which was divided by June end population estimates for each DHB multiplied by 100,000. A 95% confidence interval around each rate was calculated using the formula stated previously. Further analysis was conducted to show which DHBs had high or low proportions of African TB cases. The analysis also focused on the four regions of sub-Saharan Africa to show the variations in reported cases from the different sub-regions.

4.4.1.3.11 Clinical course and outcome

Persons with infectious TB are admitted and isolated in a hospital if they are “sufficiently unwell” or “unable to comply with community infection control precautions” (Ministry of Health, 2010). Using the ‘hospitalised’ variable, proportions of hospitalized cases by place of birth and year was calculated. The hospitalization data used in the analysis was captured in EpiSurv and may be different from the hospitalization data from the National Minimum Dataset (NMDS) of the Ministry of Health, as the NMDS data captures all hospital discharges and repeated discharges for individuals, which could lead to over reporting and previous cases being reported as discharges within the current year (Institute of Environmental Science and Research Ltd (ESR), 2015).

Deaths for all cases were assessed using the ‘died’ variable. Proportions of cases that died were calculated for each age group, sex and for the three population groups compared (African, other foreign born, NZ born). Deaths used in this analysis pertain to what was recorded in EpiSurv and may be different from the mortality data from the Ministry of Health. The decision to use data from EpiSurv was to ensure consistency and comparability for all analysis. Again, deaths reported in a year due to TB may be different

for the two data sources. The mortality collection database deaths are recorded for the year in which a person dies, which is different for EpiSurv in which deaths are assigned to the notification year (Institute of Environmental Science and Research Ltd (ESR), 2015).

4.4.2 Qualitative Research Method (Phase II)

The second phase of the study involved a qualitative inquiry into the main factors that were likely to influence TB incidence rates among the African migrants living in the Auckland region. As indicated earlier, qualitative methods were employed for its suitability in exploring the factors contributing to the relatively high TB rates, as it allowed for in-depth understanding and the opportunity to talk to the community directly affected as well as to professionals working in the area. It also provided the opportunity to propose theories to explain the observed phenomenon (Creswell, 2009; Crotty, 1998) and to make appropriate recommendations on ways to remedy the societal problem, an approach not suitable for quantitative methods. To address the research questions, participants from the African migrant communities and key informants were interviewed to generate meaning about how individual, social, economic and structural factors interacted to produce the observed patterns of a relatively high TB disease rate among African migrants.

4.4.2.1 Participants and recruitment

Sampling of participants has been identified as an important process in a qualitative research as who one interviews would shape the understanding of the phenomena under study (Morse & Niehaus, 2016). This study purposively sampled participants who had the necessary understanding of the phenomena, who were available

to participate and who were articulate and could express their thoughts clearly to help in answering the research questions (Creswell, 2013; Morse & Niehaus, 2016).

A total of nine individuals, who were above 18 years and could speak fluently in English language, were interviewed. Of this number, four were community leaders of African communities in Auckland, four were healthcare professionals and one was a participant from a charity organization in Auckland. Pseudonyms have been used in describing study participants (see table 4.1) and for participant's quotations. CL denotes (community leader), HP for health professionals and SO for support organisation. The numbers that follow these initials represent the order in which participants were interviewed; so, for instance, CL01 refers to the first community leader interviewed.

The inclusion of community leaders was to serve as a source of information on the general perceptions about TB in their communities, the existing TB control activities if any and their recommendations on the way forward for TB control strategies. The African community leaders included in this study had lived a minimum of 13 and a maximum of 26 years in NZ. These leaders were professionals working directly for the health and social sectors, and had an extensive understanding of the African communities living in NZ. Through their work, they had direct contact with the larger African community in Auckland.

The health care providers were included for their unique professional knowledge, experiences dealing with African migrants, to solicit their opinions on the challenges they face with African migrants, and for their recommendation for TB control among this sub-population group. Collectively, the four health professionals had over eighty years of professional experience in the management of TB at the community and hospital level and in managing migrant health services. The participant from the charity organization was invited to provide insight into the available support for persons with TB, the most

common support offered by the organization and for recommendations to eliminate TB. Further recruitments of these three groups of participants were discontinued after the researcher observed saturation in responses, as no new information was emerging from the interviews. Subsequent interviews were only confirming what had already been gathered in the previous interview and did not offer new insights (Morse & Niehaus, 2016). See Table 4.1 for a summary of the participants' characteristics.

Table 4.1
Participants' Demographic Characteristics

Participant	Gender	Category	Country of origin	Years in NZ
CL01	Female	Community leader	Zimbabwe	26
CL02	Male	Community leader	Zimbabwe	15
CL03	Male	Community leader	Ghana	21
CL04	Male	Community leader	Congo	13
HP01	Female	Healthcare worker	NZ born	N/A
HP02	Female	Healthcare worker	NZ born	N/A
HP03	Female	Healthcare worker	UK	54
HP04	Male	Healthcare worker	UK	16
SO01	Female	Support Organization	NZ born	N/A

To recruit participants, the researcher developed an advertisement for the study (see appendix E), which was distributed to African community organizations' leaders in Auckland through their publicly available email addresses. Contact was also made on the

phone with other community leaders whose emails were not readily available from the internet. One community leader who manages an organization, through personal contact, shared the contact details of these leaders with the researcher after he had initially consulted with the respective leaders. Those leaders that made contact with the researcher were interviewed at their preferred locations and time.

The study advertisement was also sent to three health professionals in Auckland. All three agreed to participate in the study. After the interviews, these participants recommended two TB clinicians and a leader of a TB charity organization in Auckland to be interviewed. The researcher reached out to them through contacts received from the other professionals, however, one of the clinicians did not respond to the request after two weeks and was deemed as unavailable to participate in the study. The other two were subsequently interviewed after arrangements were made on time and their preferred locations.

The recruitment of persons on treatment or those recently cured (within two years) of TB was unsuccessful, even though the study had planned to recruit between three to five of them. The initial plan was to recruit this group of participants through public health nurses after they (public health nurses) had been briefed on the study and solicited to deliver study advertisements to their African clients on treatment for TB within the Auckland region. Interestingly, there were no persons with TB of African origin on treatment between June 2016 and February 2017, the recruitment period. Efforts to recruit persons cured of TB were also unsuccessful as the researcher was informed by the Auckland region TB team that there had been no case of African TB within the past year. To address this gap, the researcher decided to intensify community advertisement for the study in the hope of identifying and recruiting persons cured of TB within the past two to three years and living within the community. Posters of the study were distributed to

African churches in Auckland, posted on community notices and to the social media platforms of community groups including Viber, WhatsApp groups and the Facebook page of the African Community Forum Incorporated of Auckland (ACOFI) – an umbrella organization of all African community organizations in Auckland. No prospective participant contacted the researcher after the community advertisements, which lasted over four months (from October 2016 to February 2017) leading the researcher to exclude this group of participants from the study.

4.4.2.2 The interview approach

The world of humans is one of conversations, wherein from early life till death we share emotions, ideas with other humans (Brinkmann, 2014). In a sense we interpret and inquire through conversations, thus far, conversations may act as a means by which language, culture and understanding of the human world is produced and reproduced (Atkinson & Silverman, 1997). Interviewing as a research process is different from everyday conversation. It has a purpose to collect data to produce knowledge about observed world phenomena by obtaining descriptions or explanations of such phenomena from the perspective of selected individuals (Brinkmann, 2014). As a research approach for generating knowledge, interview combines individual perceptions, knowledge, notion or experiences, subjectively and collectively reflecting the rich in-depth meanings of peoples realities (Brinkmann, 2007).

For this study, a semi-structured interview approach was employed. The semi-structured interview is a type of guided conversation that requires the interviewer to listen to the meanings conveyed by the interviewee (main question response), probe for further clarification (probes) and may inquire for additional information where necessary (follow up questions) (Sandelowski, 2002; Warren, 2001). It is preferred to the other interview

formats, structured and unstructured interviews, for its potential to produce insights into the meanings produced from dialogues with the participant by allowing the participant much flexibility to respond to the questions (DiCicco-Bloom & Crabtree, 2006). The interviewer, on the other hand, is encouraged to be flexible throughout the interview process, including, taking note of the meanings being communicated by interviewees and making relevant adjustments to pre-set questions, allowing for new follow up questions for subsequent interviewees in the light of emerging meanings as communicated by interviewees (Nunkoosing, 2005). This iterative process makes the interviewer an active participant in generating knowledge from the interview process (Brinkmann, 2014; Warren, 2001). Although the interviewer has the potential to be flexible, the main questions set to answer the research questions will mostly be asked using similar wording from one interviewee to the other. Thus, unlike unstructured interviews, semi-structured interviews allow the interviewer to focus the knowledge producing process on the main research questions.

All the interviews for this study were conducted in person using a one-on-one format, audio-recorded with the permission of participants, and subsequently transcribed verbatim after each interview. Individual interviews were considered suitable for this study for two main reasons. One, it allowed the interviewer to lead the interview process in a manner that helped to answer the research questions; and two, it offered more confidentiality for the interviewees. Interviewing persons individually also allowed for rapport, engendered an atmosphere of trust and provided the interviewer the space to ask sensitive (serious) questions once interviewees were reassured of their confidentiality, and felt safe and secured. Ultimately conducting one-on-one interviews for this study helped to provide participants a safe space to talk about a sensitive public health issue like TB.

An important element in the interview process was how to ensure validity in the responses from participants (Nunkoosing, 2005). It has been suggested that minimal interference or unnecessary interjections may contribute to increasing validity of responses as participants are allowed to share their knowledge or perspectives on the matter without interrupting their flow (Morse, 2012). Hence, questions were carefully designed to allow participants the opportunity and space to reflect on their experiences. Also, questions that sought to lead participants to provide expected answers from the researcher were avoided throughout the interviews. The questions that were asked in the interviews impacted the responses from participants, however, they were all invited to talk about any issue they considered to be important.

To generate knowledge about TB, an issue of public health concern, demanded appropriately engaging members of the affected communities in a subjective discussion centred on the goals in remedying observed health patterns. In doing so, the interviewees were regarded as active participants aware of the issue, directly or indirectly; and who contributed, through the interview process, to identifying possible solutions for societal good.

4.4.2.4 Development of the interviews question guide

The development of the interviews question guide was an iterative process based on the issues identified from the literature review. The first versions of the interview guides were piloted with three people who identified as Africans but were not included in this study. The wording of the questions was subsequently reviewed after thorough consideration to reflect lay perspectives on TB and to encourage participants to share stories of their experiences (direct or indirect). The interview guide was further reviewed after the first interview to accommodate the different participant groups. For example,

questions on “what is TB” was removed from the question guide for health professionals, whilst “any other comments” was included to all the question guides. Also, questions on “stigma” was reframed to produce in-depth accounts of participants. The final question guide was developed separately for the different groups of participants in this study - community leaders, health professionals and support organization (see appendix F).

The interviews with community leaders were initiated with a general question requesting participants to tell the researcher about themselves. This was to serve as an icebreaker. Part of this was to ask about the settling process in NZ and what they considered to be the differences between their home country and NZ. The latter question was to explore the issues pertaining to new Africans’ settlement in NZ, which had been identified as an important determinant for migrant health from the literature.

TB specific questions were then asked starting with issues related to individual factors. The aim of this cluster of questions was to explore participants’ general knowledge on TB, its causes, symptoms, prevention and treatment. A question on whether participants considered themselves at risk of TB was to gauge participants’ risk perception. To understand the level of TB awareness within the African community and the current sources of TB information, participants were asked about their current sources of TB information and what they might consider an effective approach to provide health information to their community members.

To explore how social factors might influence TB, community leaders were asked general questions about how people in the African community perceived TB and how they would usually treat persons with TB. Within the discussions was the notion of stigma. To explore this further, any time it came up, participants were asked about ways stigma could affect people with TB. Participants were encouraged to share stories, which

is a common tool for communication among Africans, related to stigma, if any. Social support was explored by asking participants about existing support for persons with TB from the family, their communities and society.

To understand how economic factors might contribute to the observed phenomenon, questions to community leaders were concerned with the general financial conditions of Africans, employment and costs associated with TB. The aim was to understand the interplay between these issues and how they increase vulnerability of members of the community to TB. A question on employment post successful completion of TB treatment was included to explore the long-term effects of TB on employment, which was a gap identified in the literature.

Structural factors including health system issues, and TB specific issues were discussed. The questions posed were aimed at understanding African migrants' perception about their healthcare providers, TB treatment adherence issues, TB prevention, the role of immigration policy, the barriers to TB services and any other concerns participants had in relation to the health of African migrants.

For healthcare professionals, the interviews began in a similar way to community leaders. Healthcare professionals were asked about the TB services, support systems and costs associated with TB. These questions were follow up from initial discussions with community leaders and aimed at triangulating and clarifying some of their concerns. Questions related to their encounters with Africans were also asked to explore their concerns in dealing with Africans. Issues of stigma, barriers to TB services and the impact of immigration policy were further discussed with health professionals to understand how Africans coped with their new life with TB.

The questions for the participant from the charity organization followed a similar pattern as that of the health professionals. Additional questions related to how persons with TB were identified for support and the support types available. The questions were to provide details on support systems and to understand which support system was common and why.

4.4.2.5 Data analysis

The study employed thematic analysis in order to make sense of the qualitative interview data. Thematic analysis has been defined by Braun and Clarke (2012) as “a method for systematically identifying, organising and offering insight into patterns of meaning (themes) across a data set” (pg. 57). This method of analysis offers a unique approach to identify and make sense of the important and common meanings communicated in the different data sets related to a topic. Thematic analysis is flexible, allowing data to be analysed systematically in different ways (Braun & Clarke, 2012). It is suitable for providing detailed analysis of textual data; and most importantly, it is compatible with critical realism, the philosophical framework underpinning this study (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006).

A hybrid thematic analysis, involving both the inductive (data driven) and the deductive (theory or literature driven) approach, adopted from what Braun and Clarke (2006) termed ‘phases’ thematic analysis was used. The deductive approach to coding and analysis involves the application of theories, constructs, concepts or questions to code and interpret data (Braun & Clarke, 2012). In this, the themes are derived largely from the theories or research questions. Conversely, an inductive approach is data driven focusing on meanings within the data (Braun & Clarke, 2012). In this approach, themes derive from the data. In Braun and Clarke’s work, they clearly differentiated the process

of thematic analysis into six phases: familiarization with data; initial codes generation; generating themes; reviewing and revising themes; definition of themes and their names; and reporting.

In this study, themes that were captured represented the important or main (patterned) responses from the interview transcripts in relation to the research questions (Fereday & Muir-Cochrane, 2006). The coding process was iterative and began after recorded interviews were transcribed and entered in NVivo 11 software for windows, a computerised software for management of qualitative data. A list of codes, their labels, definitions and criteria for their use were developed manually from the interview question guide prior to the coding process, and applied to all the interview transcripts to identify interesting phrases, concepts and ideas related to the codes. The codes were entered as nodes in NVivo and the text or extracts from the transcripts were coded by matching the text to the codes. The other codes that were identified inductively from the coding process were assigned to new nodes. The codes that were identified from the reading of the transcribed data related to ideas and concepts that were important in helping the researcher to organize, describe and explain the phenomenon under study (Boyatzis, 1998).

The connections between the different codes, how they related and their prevalence (number of times used by participants) within the data set were considered in identifying and categorising them into themes, which were further grouped into higher level clusters (see appendix G). Thus a balance between prevalence and importance of the patterned responses in addressing the research questions guided the iterative process of identifying and naming themes (Boyatzis, 1998). Thematic analysis is flexible on how meanings are reported from data. One could report at the semantic level, which is the obvious meanings from the data, or the latent meanings, which involve interpreting the

underlying ideas or assumptions underpinning that explicitly communicated in the data (Braun & Clarke, 2012). In this study, the themes were identified at the semantic level (semantic themes), wherein explicit meanings as communicated by the participants and recorded in the data, were identified guided by the research questions. The semantic approach in identifying themes is justified within the critical realist epistemology, as people's experiences, the empirical reality, may be communicated in conversation and meaning can be made directly from such experiences (Braun & Clarke, 2006).

4.5 Researcher Reflexivity

Throughout the study I was aware of the constant internal dialogue within myself about the quantitative and qualitative data sets and the meaning I could derive from them based on what I knew and wanted to know. This process of reflection, an integral part of the process of knowledge generation has been referred to as reflexivity (Smith, 2006).

Although, I had some professional knowledge and working experience in the field of TB and HIV, my understanding of the NZ health system and the major issues of concern to the African migrant communities was limited. This was helpful as I approached this study without any frame to interpret the results, but with an open mind eager to understand rather than to impose my understanding, which was in line with the critical realist perspective.

The process of selecting denominators for the quantitative data analysis intrigued me. The choice of place of birth data and the categorisation of the findings into the three groups was made after a series of consultations and review of the Ministry of Health's ethnicity data protocols, which revealed interesting findings about the process of ethnicity data capture and utilisation in NZ. My initial reaction to the ethnicity data was one of

surprise as the African ethnicity was fewer than anticipated. However, further investigation led to changes in the original plan, which was to analyse data by ethnicity. While this was evolving, it helped me develop a better understanding of the usefulness of data collection during a census. Critical questions, such as how we engage minority communities to get counted, and what better ways can Africans be classified for ease of completion of the ethnicity questions, remain and would continue to engage my attention.

For each interview, I took notes, which were related to my impressions about the interview process and the participant. These were used together with the interview transcripts to generate meaning to answer the research questions. These notes were also used to shape follow up questions for subsequent interviews aimed at bringing more clarity and to help in effectively answering the research questions.

I adopted strategies to ensure rigour inherent throughout the research process (Morse et al., 2002). Whilst thematic analysis is flexible and allows the researcher to make subjective meanings from interview data sets, care must be taken to ensure that the data analysis process is not guided by personal motives and biases (Braun & Clarke, 2006). As Morse and colleagues (2002) argue, “strategies for ensuring rigour must be built into the qualitative research process per se” and can include investigator responsiveness, methodological coherence and member verification. Verification, the process of checking or confirming interpretations to ensure only commonly identified themes were reported (Lincoln, 1995; Sandelowski, 1993), was done in conjunction with my supervisors who reviewed all the themes identified from the interview data sets. I addressed the aspect of investigator responsiveness by moving beyond the narrow focus on previously held theoretical assumptions guided by the interview questions, to carefully looking for meanings communicated by participants within the rich interview data (Morse et al., 2002). In doing so, a hybrid approach (Braun & Clarke, 2006) was used and led to

themes that were not anticipated from the priori codes developed for the analysis. I also ensured congruence between the research method adopted and the research questions that I sought to answer, and provided sufficient evidence from the data using participant quotes (excerpts) to support the presentation of the findings in chapter six as well as reconfirming these findings by linking the findings to existing theories and literature (Morse et al., 2002).

4.6 Summary

The current chapter presented the methods that were employed in this study and justified why these methods were selected over the other possible approaches available. The chapter was based on the conceptual framework developed from a socio-ecological perspective of health underpinned by a critical realist philosophy. It provided a detailed account of how the two phases of the study were conducted. The next chapter presents the results from the implementation of the current chapter and highlight the key findings from the analysis of TB surveillance data (phase I).

Chapter Five – Phase I: Quantitative Results

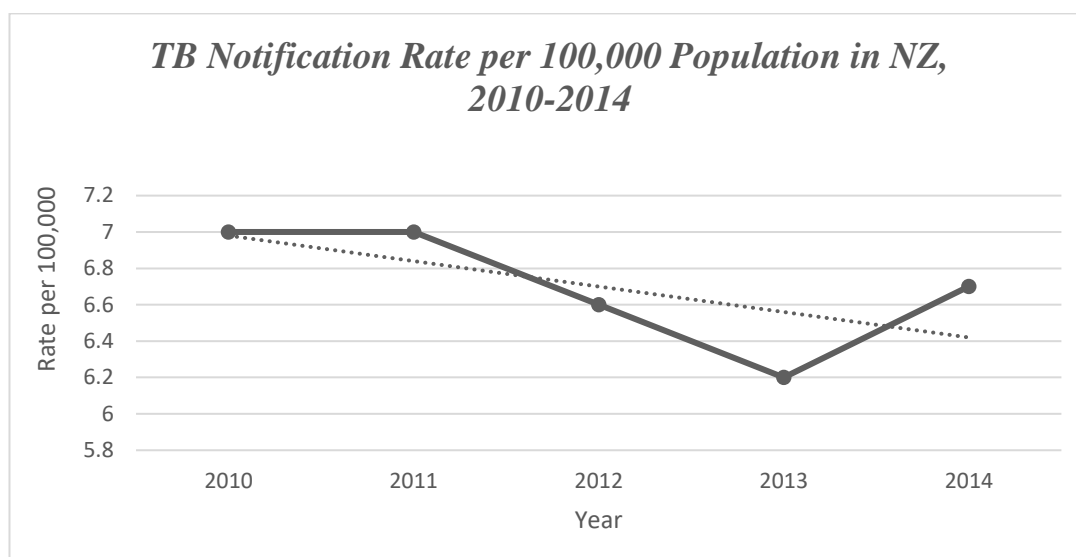
5.0 Introduction

The preceding chapter elaborated how data for both phases of the study were collected and analysed. This chapter presents the findings from the epidemiological analysis of all confirmed and probable TB cases (new cases and relapsed or reactivated cases) in New Zealand from 2010 to 2014. The analysis focused on three population groups categorised by place of birth – cases born in New Zealand (NZ), cases born in sub-Saharan Africa (referred to as Africans) and other foreign-born persons (all cases born outside NZ but not in sub-Saharan Africa). First the findings from the overall TB data will be presented, followed by the categorisation by place of birth. The chapter ends with a discussion of the findings and the limitations.

5.1 Notifications of TB Disease

From 2010 to 2014 a total of 1,479 cases of TB disease were notified (1,423 new cases; 56 relapsed or reactivation cases). There was a slight decline of 0.66% in the annual number of TB disease notified between 2010 and 2014 (302 in 2014 compared to 304 in 2010). Trend analysis using simple linear regression showed a statistically insignificant reduction of less than 1 case (0.14) per 100,000 population annually over the period ($F(1,3) = 2.41, p=0.2184$) (see figure 5.1).

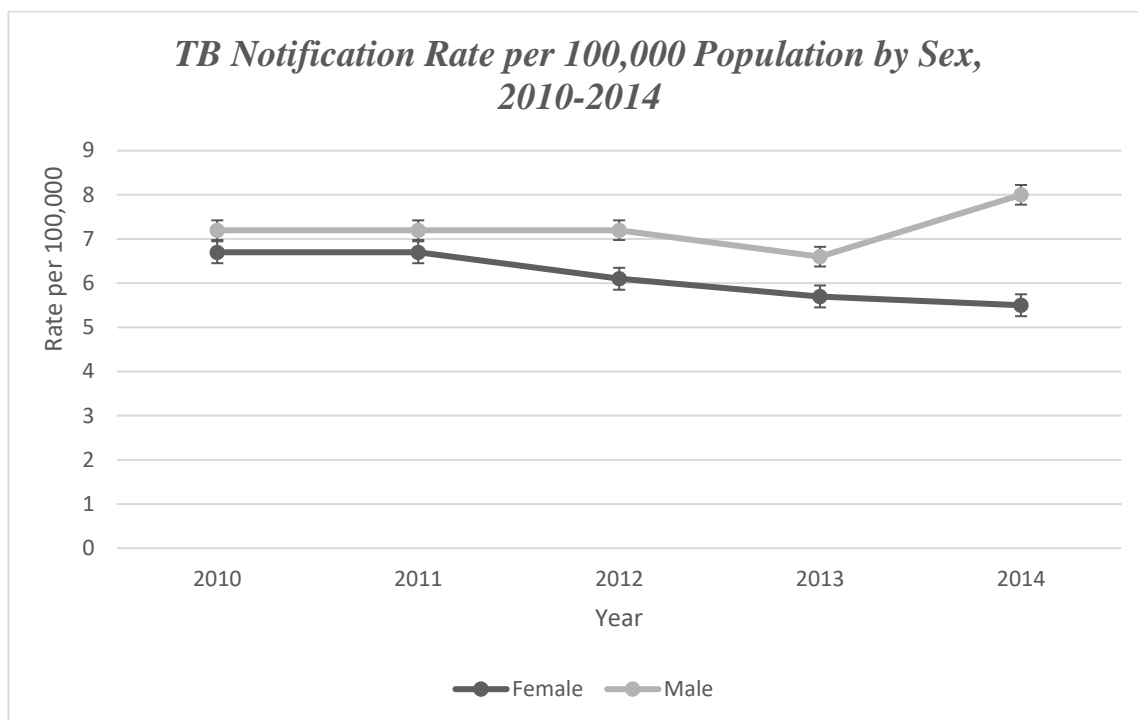
Figure 5.1



5.1.1 Notifications of TB by Sex

Of the 1,479 cases of TB notified within the period, 784 were males representing 53% while 695 cases (47%) were females. There was a statistically significant difference in the number of cases between males and females ($\chi^2 (1) = 5.36$, $p = 0.02$). The cumulative annual notification rate over the period was higher for males (7.2 per 100,000) compared to females (6.1 per 100,000) with TB rates among females declining while that among males increased (see figure 5.2). However, both the decline in female and rise in male rates were less than 1 per 100,000 population annually over the period and statistically insignificant at 95% confidence ($F (1,3) = 2.41$, $p = 0.22$), ($F (1,3) = 0.34$, $p = 0.60$) respectively.

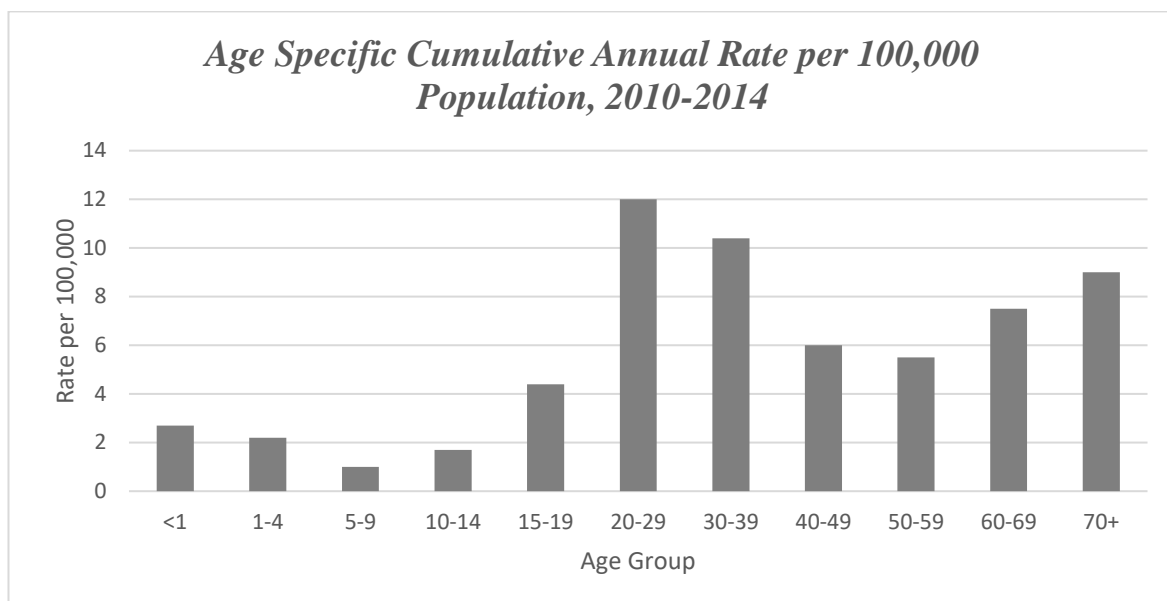
Figure 5.2



5.1.2 Notifications of TB by Age

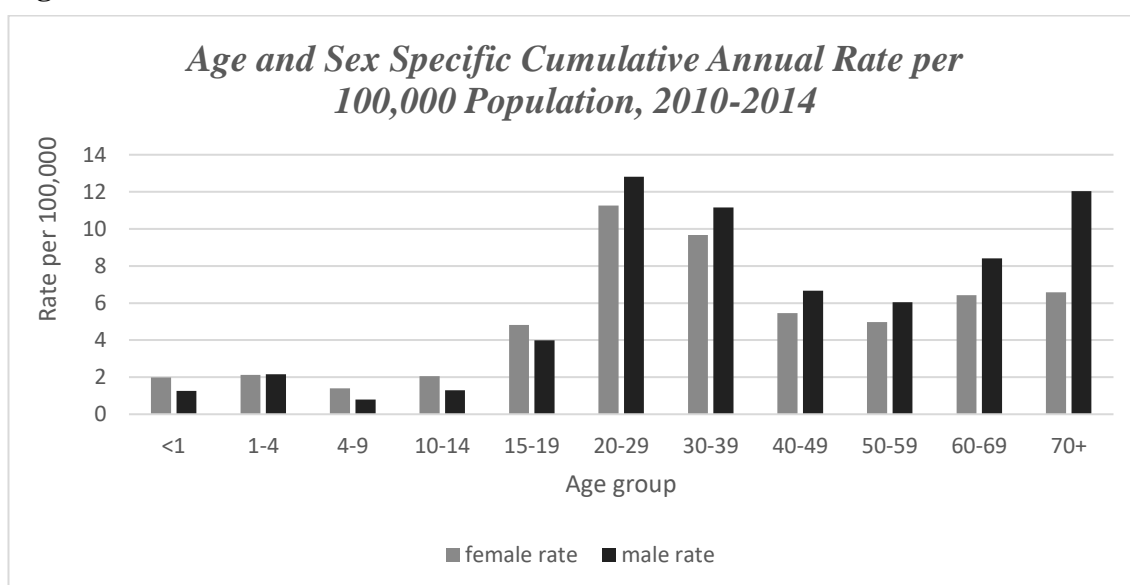
The age-specific TB rates were different over time and the result was statistically significant ($\chi^2(10) = 24.16$, $p < 0.01$). The 20 to 29 age group (12.0 per 100,000, 355 cases) recorded the highest age specific cumulative incidence rate, followed by the 30-39 age group (10.4 per 100,000, 289 cases). The lowest rate was among the 5-9 age group (1.0 per 100,000) (see figure 5.3).

Figure 5.3



For both males and females, the highest cumulative rate of TB was among the 20-29 age group. Among the males, those aged 70+ recorded the second highest cumulative rate of TB (12.0 per 100,000 population), which was even higher than the rate among females 20-29 years and about twice the rate of females 70+ (6.6 per 100,000 population) (see figure 5.4).

Figure 5.4

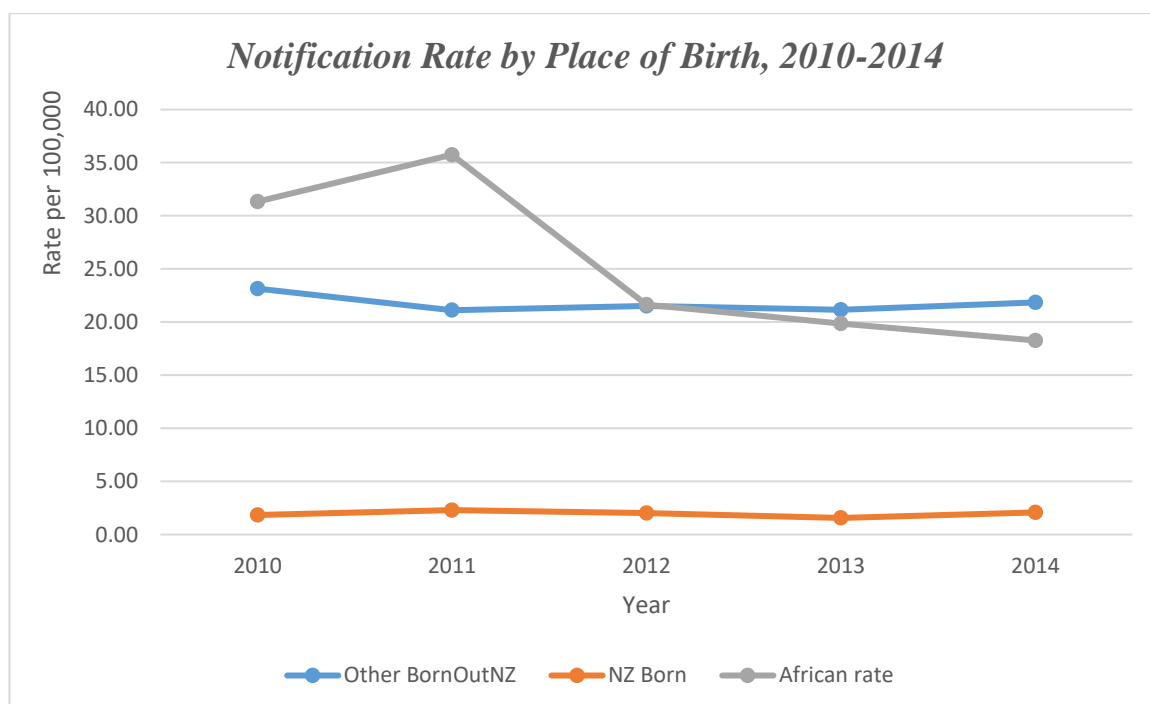


5.1.3 Notification by Place of Birth

The number of cases (1,146 cases, 77.48%) among overseas born were more than three times that of persons born in NZ (331 cases, 22.38%) (see figure 5.5). Among the foreign-born persons with TB, 7.5% (86 of 1,146) were born in a sub-Saharan African country while 1,060 cases (92.5%) were “other foreign born”.

Trend analysis showed the crude incidence rate of TB among other foreign and NZ born declined by 0.25 cases per 100,000 population and by 0.02 cases per 100,000 population per year over the period respectively. The decline in the rate among the other foreign and NZ born were both statistically insignificant at 95% confidence (other foreign born; $F(1,3) = 0.91$, $p = 0.41$, NZ born; $F(1,3) = 0.06$, $p = 0.83$). Details on the African TB rates are provided in the section below.

Figure 5.5

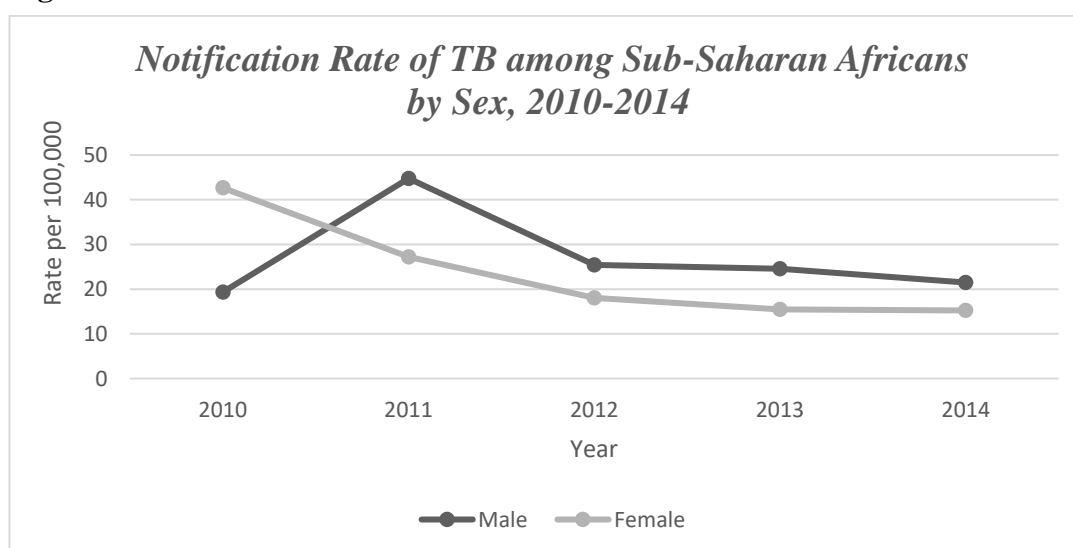


5.1.4 TB Notifications among Sub-Saharan Africans

A total of 86 TB cases (81 new cases, 5 relapse cases) were notified from 2010 to 2014 among persons born in sub-Saharan African countries, representing a cumulative incidence rate of 24.93 per 100,000 population. The cumulative incidence rate was slightly higher among persons born in sub-Saharan Africa compared to other foreign-born persons (21.75 per 100,000) and about 12 times more than the rate among the NZ born population (1.96 per 100,000).

The rate of TB among sub-Saharan Africans declined by 4.2 cases per 100,000 population from 2010 (31.32 per 100,000) to 2014 (18.27 per 100,000), but the decline was not statistically significant at 95% confidence ($F(1,3) = 8.6$, $p = 0.06$). The cumulative incidence rate among African males was slightly higher (26.84 per 100,000, 45 cases) than female Africans (23.12 per 100,000, 41 cases), but the difference between the two was not statistically significant over the period ($\chi^2(16) = 20$, $p = 0.22$) (see figure 5.6). Among African males, the rate of TB declined by 1.6 cases per 100,000 population over the period, but was statistically insignificant ($F(1,3) = 0.2$, $p = 0.69$); while that among African females showed a statistically significant decline by 6.7 cases per 100,000 population per year over the period at 95% confidence ($F(1,3) = 13.34$, $p = 0.04$).

Figure 5.6



The Africans with TB (mean age, 39.4 years) were relatively younger compared to other foreign (mean age, 42.0 years) and NZ born (mean age, 42.4 years). A one-way ANOVA test was conducted to compare the ages among the three groups. There was no statistically significant difference in age between the three groups compared ($F(2) = 0.76$, $p = 0.47$) (see figure 5.7).

Among the African males, the highest proportion of TB cases was recorded among the 20-29 age group (24.4%, 11 cases), followed by 30-39 (22.2%, 10 cases) and 40-49 (22.2%, 10 cases) age groups. For females, the highest proportion of cases was reported among the 20-29 (26.8%, 11 cases) and 40-49 (26.8%, 11 cases) age groups. No case of TB was reported among the <15years age group within the period (see table 5.1).

Figure 5.7

Mean Ages and Confidence Intervals for African, Other Foreign and NZ Born, 2010-2014

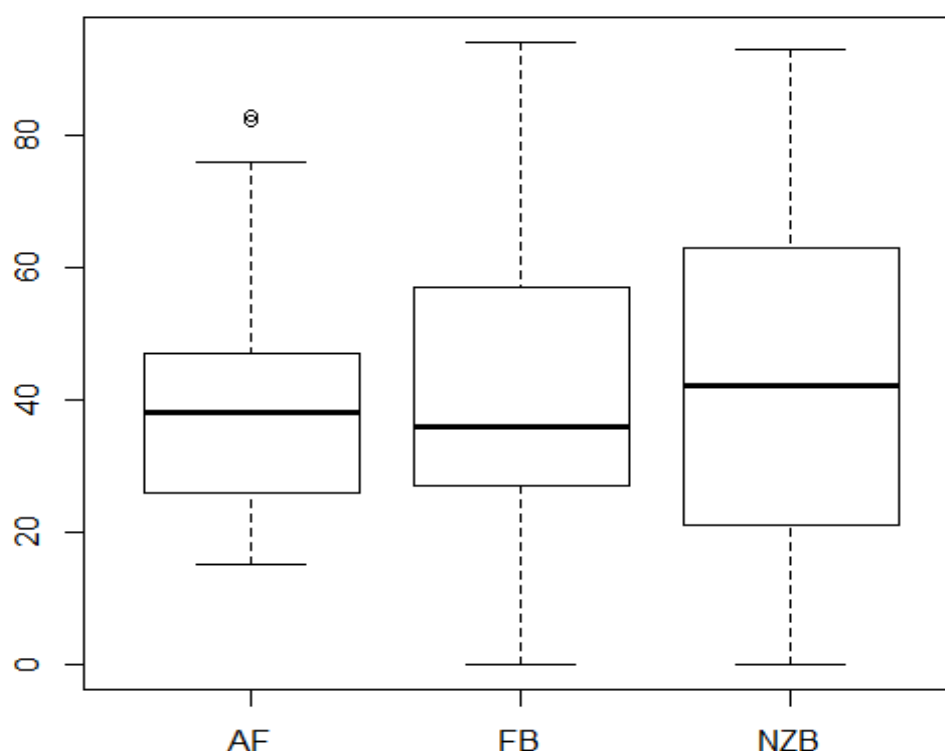


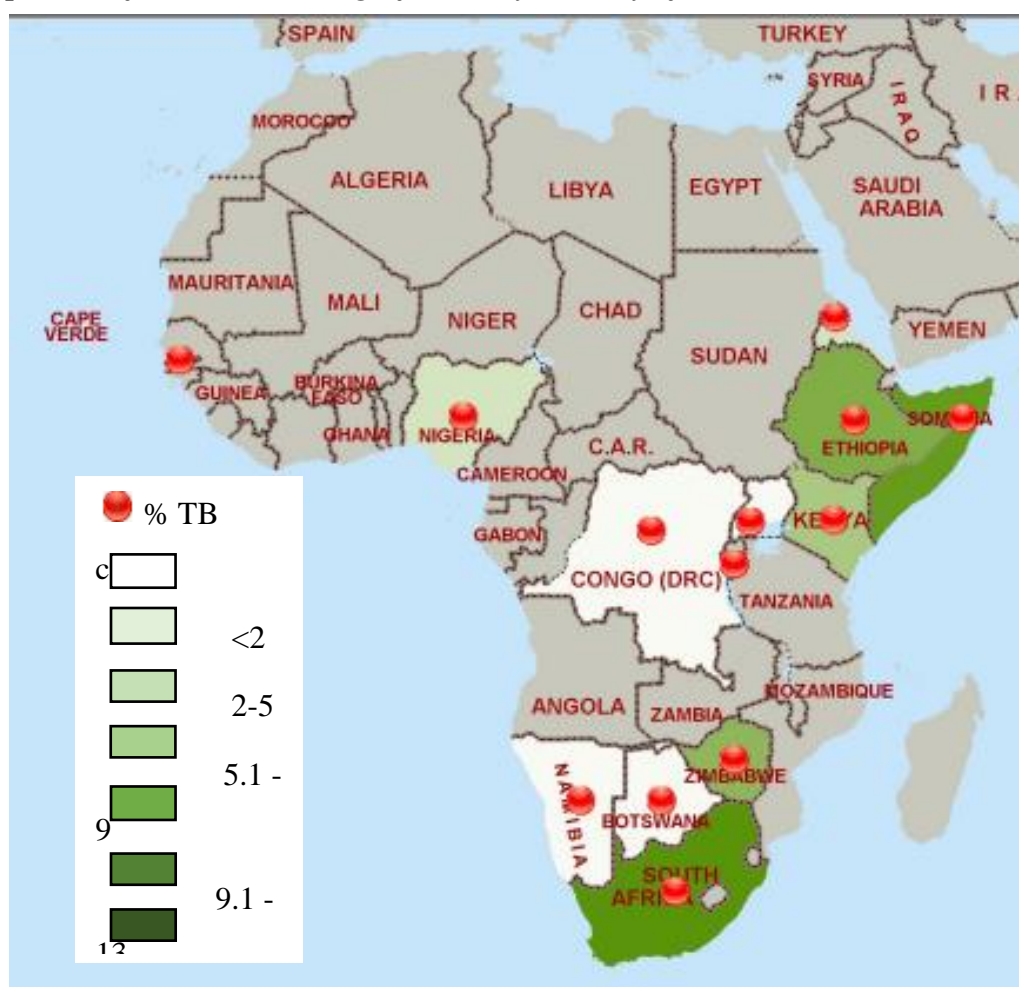
Table 5.1***TB Notifications among Africans by Sex and Age Groups***

Age group	Male		Female	
	cases (n)	Proportions (%)	cases (n)	Proportions (%)
<15	0	0	0	0
15-19	3	6.7	1	2.4
20-29	11	24.4	11	26.8
30-39	10	22.2	10	24.4
40-49	10	22.2	11	26.8
50-59	5	11.1	6	14.6
60-69	3	6.7	0	0
70+	3	6.7	2	4.9
Total	45	52.3	41	47.7

Within the period, Africans with TB originated from 13 African countries: 42 cases (48.8%) migrated from East Africa; 40 (46.5%) from Southern Africa; three (3.5%) from West Africa and; one (1.2%) from Central Africa. The highest number of cases came from South Africa (28 cases; 32.6%), followed by Somalia (21; 24.4%), Ethiopia (12; 14.0%) and Zimbabwe (9; 10.5%). Sixty-one cases representing 70.9% of all African TB cases originated from three countries: South Africa, Somalia and Ethiopia (figure 5.8).

Figure 5.8

Proportion of TB Cases among Africans by Country of Birth, 2010-2014



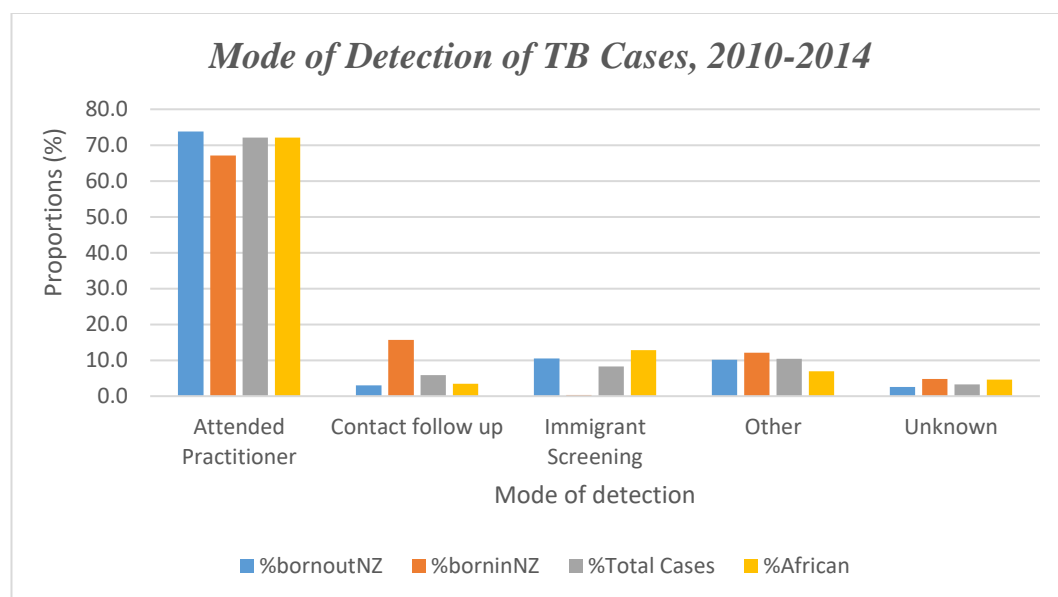
5.1.5 Mode of Detection of TB Cases

The most common mode of detection for all TB cases was when persons with symptoms visited a general practitioner (72.1%, 1067 cases). This was followed by other sources (10.4%, 154 cases) and by immigrant screening (8.3%, 123 cases) (see figure 5.9).

Among Africans, TB cases similarly were commonly detected when persons attended a general practitioner (72.1%, 62 cases). Immigrant screening was the second highest mode of detection (12.8%, 11 cases). The pattern was similar for other foreign-

born cases; 73.8% detected while attending a general practitioner, and 10.5% through immigrant screening.

Figure 5.9



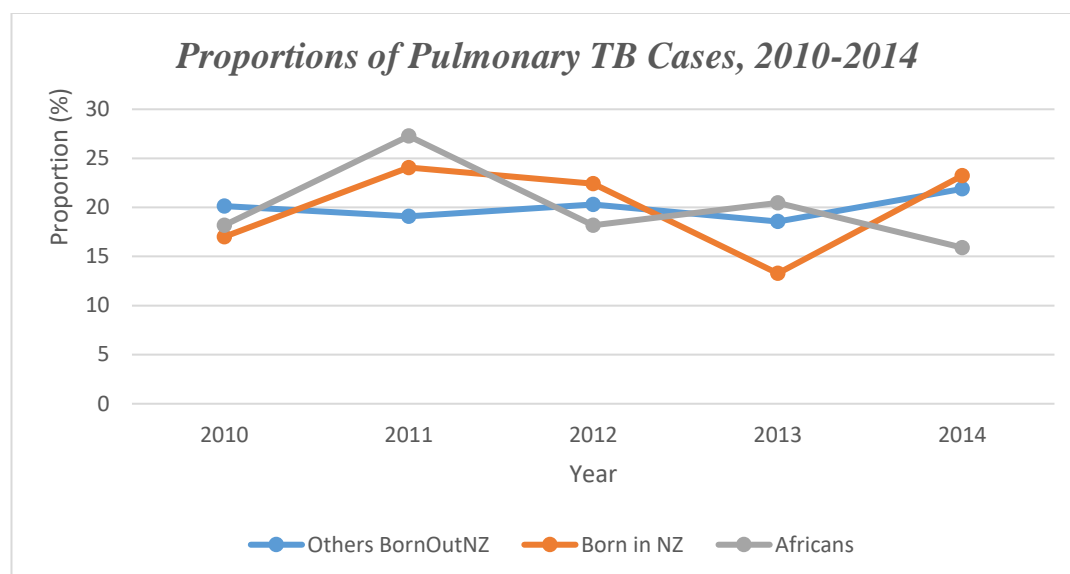
Over the five-year period, a total of 65 cases were reported as part of an outbreak. There were statistically significant differences ($\chi^2(3) = 50.0, p < 0.01$) in the proportion of cases identified in the outbreak investigations among the different age groups over the period; <15years (26 cases, 40.0%), 15-39 (29 cases, 44.6%), 40-59 (8 cases, 12.3%) and 60+ (2 cases, 3.1%). Persons born in NZ had the highest proportion of cases linked to an outbreak (51 cases, 78.5%) compared to other foreign born (14 cases, 21.54%). There was no reported case linked to an outbreak of TB among Africans.

5.1.6 Site of TB

Data on the site of TB infection were recorded for 98.6% (1458 cases) of the cases notified from 2010 to 2014. Of these, 857 were pulmonary TB cases (58.8%). The proportion of pulmonary TB cases varied for the population groups compared. Among persons born in NZ, there were cumulatively more cases of pulmonary TB (72.8%) than

extra-pulmonary compared to other foreign born (53.9%) and Africans (51.2%) (see figure 5.10).

Figure 5.10



5.1.7 Occupation

Data on coded occupation were available for 1,462 cases representing 98.9% of the total TB cases. In the analysis, occupations were classified into five main groups: healthcare workers; retired; students; unemployed; and other occupations. The ‘other occupations’ group encompassed all the other reported occupations excluding the four.

One in five (20.0%) of all reported TB cases among Africans were unemployed. Among NZ born the retired group accounted for the highest proportion of TB cases (17.1%) followed by the unemployed (11.3%) (Table 5.2). For other foreign born, the highest proportion was among the retired (13.8%), followed by students (13.4%).

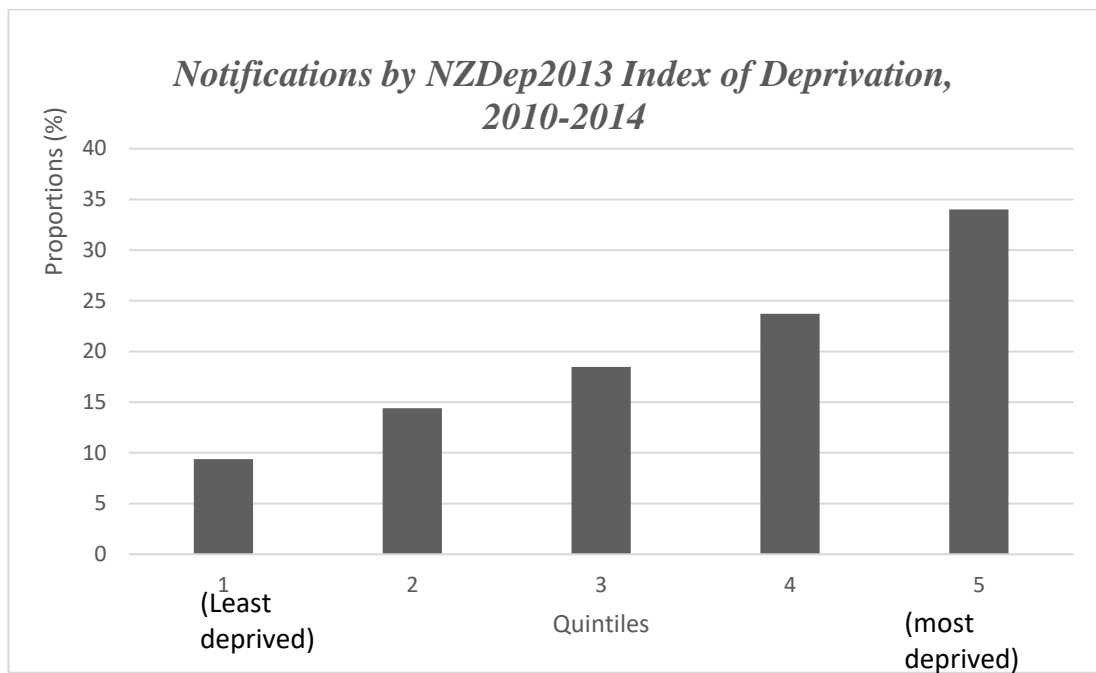
Table 5.2***Occupations for Notified TB Cases among the Three Population Groups, 2010-2014***

Occupation classification	African		NZ born		Other foreign born	
	Cases (n)	Proportion (%)	Cases (n)	Proportion (%)	Cases (n)	Proportion (%)
Healthcare workers	12	14.1	7	2.1	53	5.1
Student	9	10.6	32	9.8	140	13.4
Retired	5	5.9	56	17.1	144	13.8
Unemployed	17	20.0	37	11.3	70	6.7
Other occupations	42	49.4	195	59.6	634	60.9
Total	85	100.0	327	100.0	1041	100.0

5.1.8 Notification of TB by NZDep2013 index of deprivation

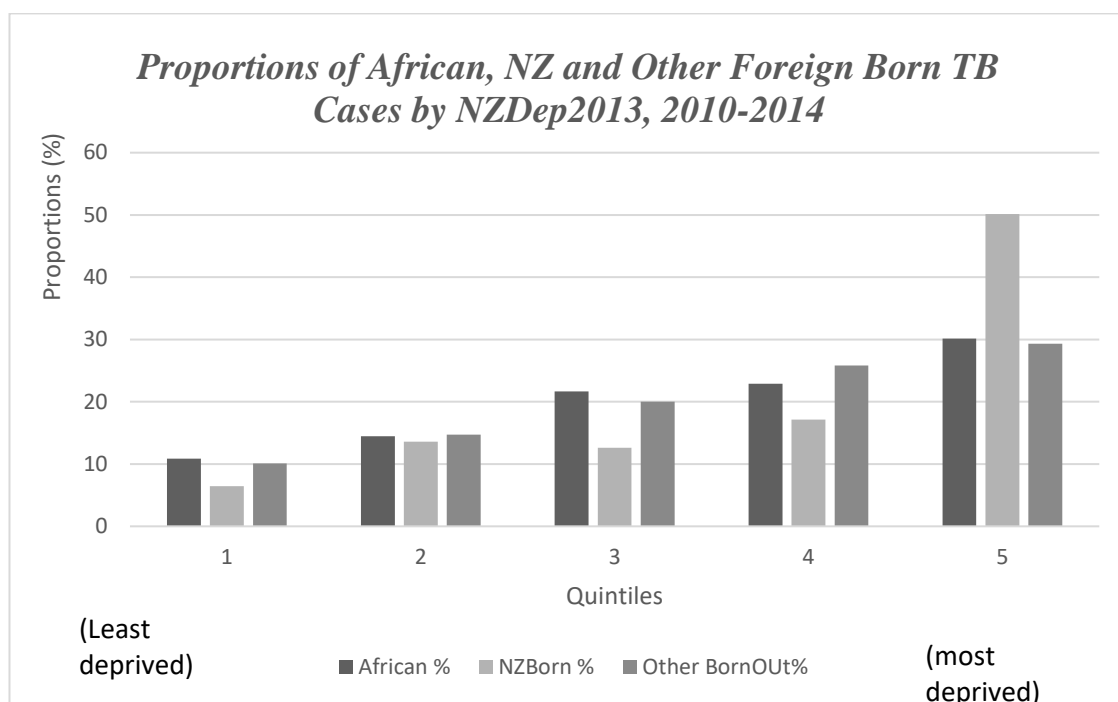
The NZDep2013 index of deprivation was reported for 95.2% (1408 cases) of all TB cases. The analysis showed the highest proportion of TB cases were reported among people living in the most deprived areas in NZ; quintile 5 (34.0%, 479 cases) and quintile 4 (23.7%, 334 cases), whilst the smallest proportions were reported from the least deprived areas; quintile 1 (9.4%, 132 cases) (see figure 5.11). There were statistically significant differences between the proportions of notified cases from the least and most deprived quintiles over time ($\chi^2(4) 17.84, p < 0.01$).

Figure 5.11



Among Africans, there was a statistically significant difference in the proportions of TB cases ($\chi^2(4) = 11.41, p = 0.02$) between the least and most deprived quintiles over the period. The largest proportion of TB cases was reported from the most deprived areas; quintile 5 (30.12%, 25 cases) and quintile 4 (22.9%, 19 cases). Africans living in the least deprived areas, quintile 1 (10.8%, 9 cases), contributed the smallest proportion of TB cases (see figure 5.12). Among other foreign and NZ born, the pattern was similar. The highest proportions were from the most deprived quintiles, 29.3% and 50.2%, while the least deprived quintiles had the lowest proportions, 10.1% and 6.5% respectively.

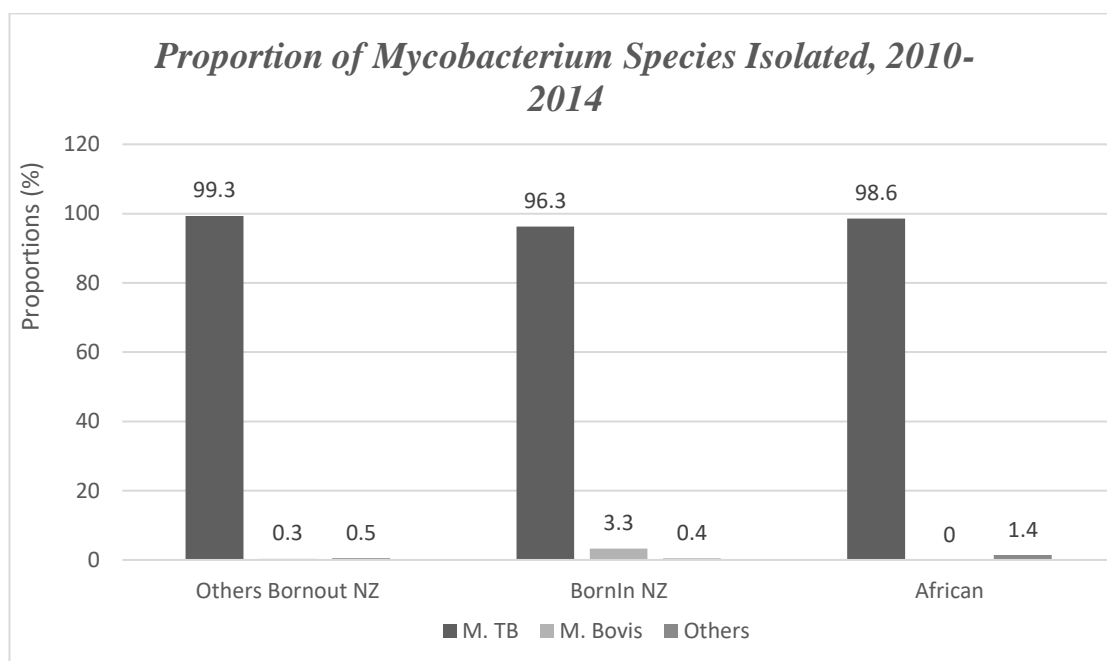
Figure 5.12



5.1.9 Culture Confirmation and Mycobacterial Species

Culture confirmation and mycobacterium species isolation were reported for 80.5% of all cases. *Mycobacterium tuberculosis* (98.6%, 1173) was the most commonly isolated species among Africans (98.6%), persons born in NZ (96.3%) and other persons born outside NZ (99.2%). In total, there were 11 cases (0.9%) due to mycobacterium *bovis*. Of the three population groups, persons born in NZ had the highest proportion of *M. bovis* (3.3%, 8 cases), followed by other foreign born. There was no case due to *M. bovis* among Africans (see figure 5.13).

Figure 5.13



5.1.10 Drug Susceptibility

Data on antimicrobial susceptibility were available for the isolates from all culture positive TB cases (1,190 cases). The five routinely tested antimicrobials were Isoniazid (H), Rifampicin (R), Ethambutol (E), Pyrazinamide (Z), and Streptomycin (S). Over the period, a proportion of 76.4% (909 cases) were fully susceptible to all five antimicrobials, whereas, 0.3% (3 cases) were resistant to all five. A total of 16 (1.3%) MDR TB cases, defined as resistance to at least isoniazid and rifampicin, were reported: 17.1% (203 cases) and 4.6% (55 cases) of the isolates were resistant to one and two antimicrobial agents respectively. A summary of the antimicrobial resistance patterns is provided in table 5.3.

Table 5.3***Antimicrobial Resistance Patterns for TB Isolates, 2010-2014***

Antimicrobial	Cases (proportion, %)
Fully susceptible	909 (76.4)
Resistant to 1 agent	203 (17.1)
Isoniazid(0.1mg/L) (H)	85 (7.1)
Rifampicin (R)	19 (1.6)
Ethambutol (E)	7(0.6)
Pyrazinamide (Z)	17(1.4)
Streptomycin (S)	75(6.3)
Resistant to 2 agents	55(4.6)
H+R (MDR-TB)	16 (1.3)
H+E	6 (0.5)
H+Z	7(0.6)
H+S	26(2.2)
Resistant to 5 agents	
H+R+E+Z+S	3(0.3)

Of the three groups compared, resistance to isoniazid was most common among isolates from other foreign-born persons (8.2%) and Africans (4.2%), with persons born in NZ (1.7%) reporting the least. There was no reported case of resistance to rifampicin and ethambutol from NZ born and Africans. The highest proportion of resistance to streptomycin was from other foreign-born persons (7.3%), followed by Africans (4.2%). Isolates from NZ born persons recorded the highest proportion of resistance to pyrazinamide (2.5%) (see table 5.4). All five African relapse cases were fully susceptible to the antimicrobials.

Table 5.4***Antimicrobial Resistance by Place of Birth, 2010 – 2014***

Antimicrobial	NZ born		Other foreign born		African	
	Cases	% resistant	Cases	% resistant	Cases	% resistant
Isoniazid (0.1mg/L)	4	1.7	78	8.2	3	4.2
Rifampicin	0	0	19	2.2	0	0
Ethambutol	0	0	7	0.8	0	0
Pyrazinamide	6	2.5	11	1.3	0	0
Streptomycin	7	2.9	64	7.3	3	4.2

5.1.11 Notification by DHB

Auckland DHB contributed the highest number of TB cases (325) representing a cumulative incidence rate of 14.2 per 100,000 (12.7 – 15.8, 95% CI). It consistently had the highest rate over the period except for 2013 when Capital and Coast reported the highest rate (12.6 per 100,000). Capital and Coast recorded the next highest cumulative rate 10.9 per 100,000 (9.2 – 12.6, 95% CI) followed by Counties Manukau 10.8 per 100,000 (9.5 – 12.1, 95% CI), South Canterbury (0.7 per 100,000), Southern (2.0 per 100,000), and Whanganui (2.2 per 100,000) which recorded the least cumulative rates respectively.

Eight DHBs (Hawke's Bay, Lakes, Nelson Marlborough, Northland, South Canterbury, Wairarapa, West Coast, and Whanganui) out of the 20 did not report any case of TB with an African origin over the five-year period. Capital and Coast had the highest proportion of the cumulative TB cases among Africans (23.3%, 20 cases) followed by Auckland (17.4%, 15 cases) and Waitemata DHBs (15.1%, 13 cases).

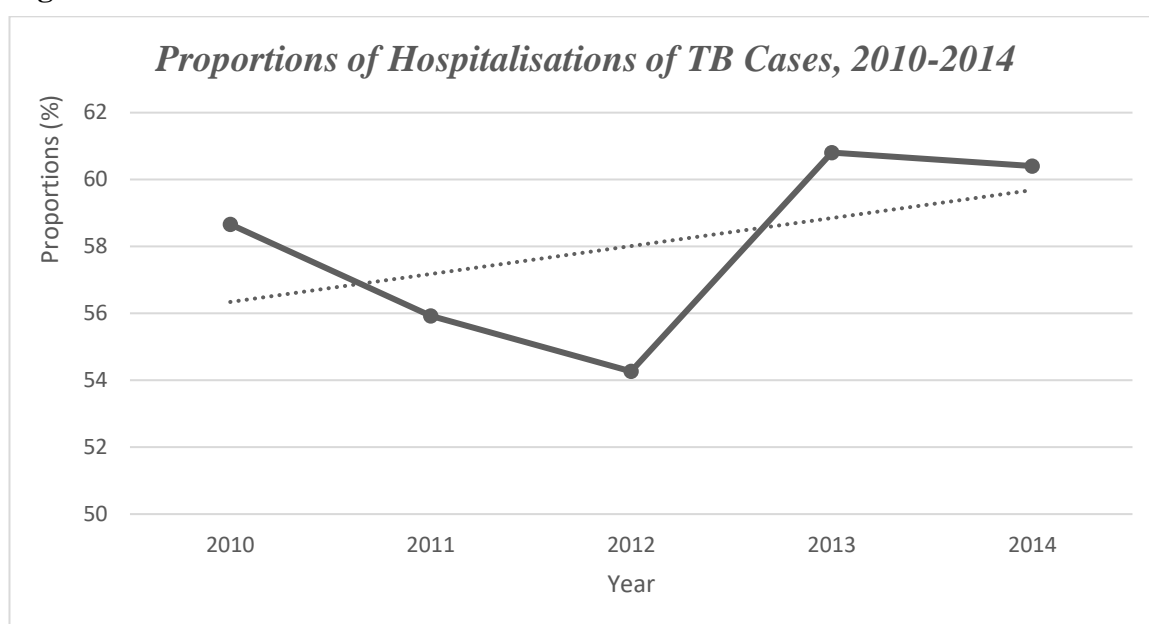
For both NZ and other foreign born, a case of TB was notified in each DHB. Auckland reported the highest proportion of cases among other foreign born (25.5%, 268

cases), whilst the highest proportion reported among NZ born was by Counties Manukau. South Canterbury DHB recorded the lowest proportion of TB cases for both NZ born (0.3%, 1 case) and other foreign born (0.1%, 1 case).

5.1.12 Hospitalizations

Data on hospitalizations were recorded for 99.3% of all notified cases. Over half of all cases reported from 2010 to 2014 were hospitalized (57.97%). The proportion of cases hospitalized slightly increased albeit statistically insignificantly by about 1% annually from 2010 (58.67%) to 60.40% in 2014 ($F(1,3) = 0.82$, $p = 0.43$) (figure 5.14).

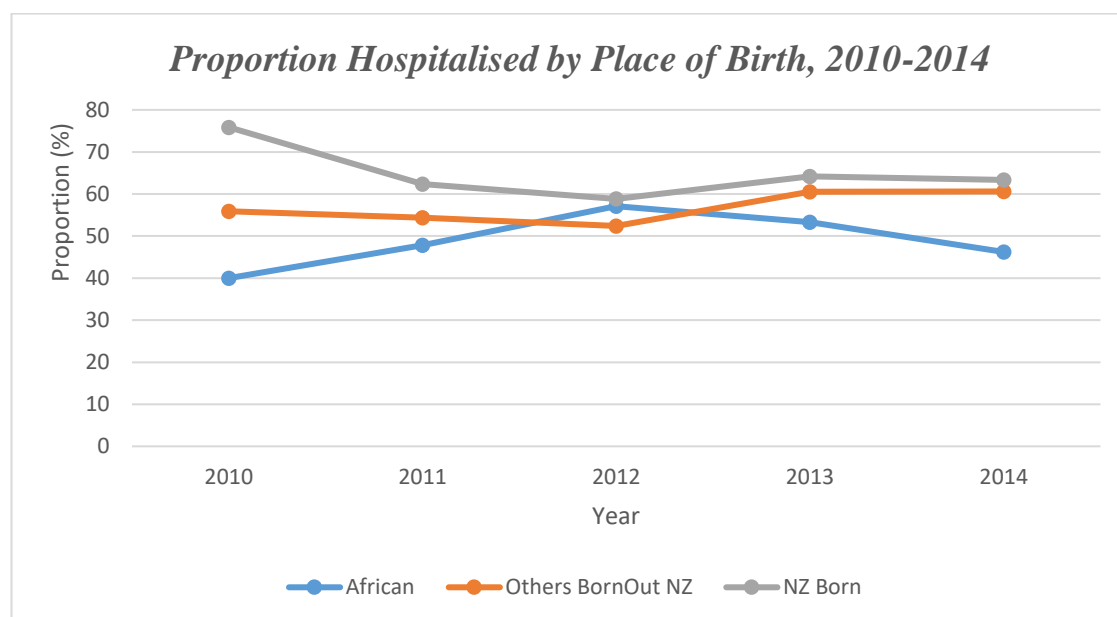
Figure 5.14



The proportion of hospitalizations for TB was lowest for Africans (47.7%) compared to NZ born cases (64.5%) and other foreign born (56.7%). Hospitalizations among NZ born cases declined by about 2% per year over the period but the extent of decline was not statistically significant ($F(1,3) = 1.4$, $p = 0.32$). Conversely the proportion

of hospitalizations increased statistically insignificantly by about 2% over the period among Africans ($F(1,3) = 0.68$, $p = 0.47$) and by about 2% among other foreign-born persons ($F(1,3) = 2.4$, $p = 0.22$) (figure 5.15).

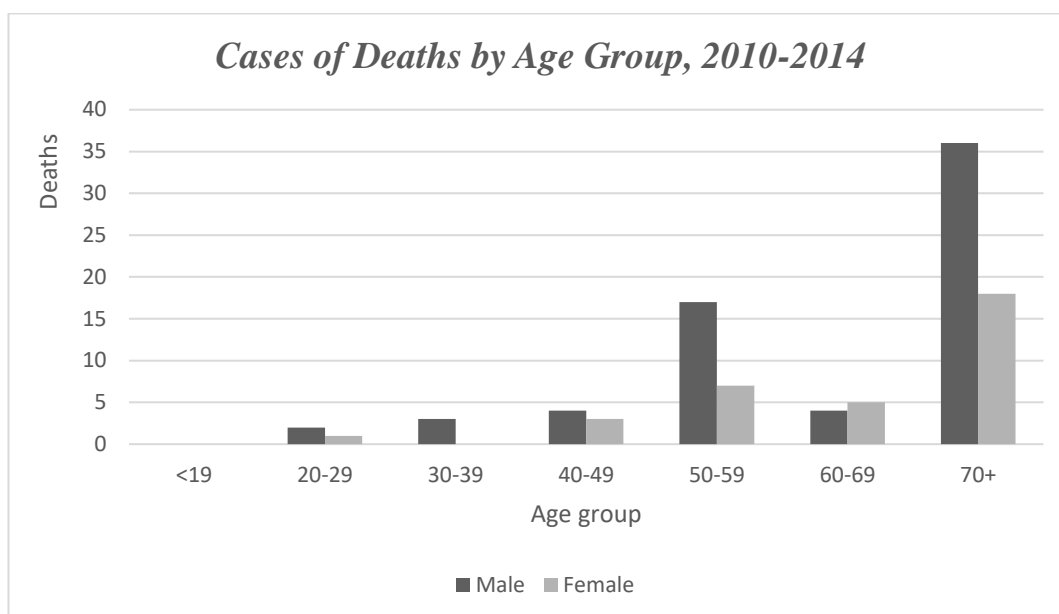
Figure 5.15



5.1.13 Deaths

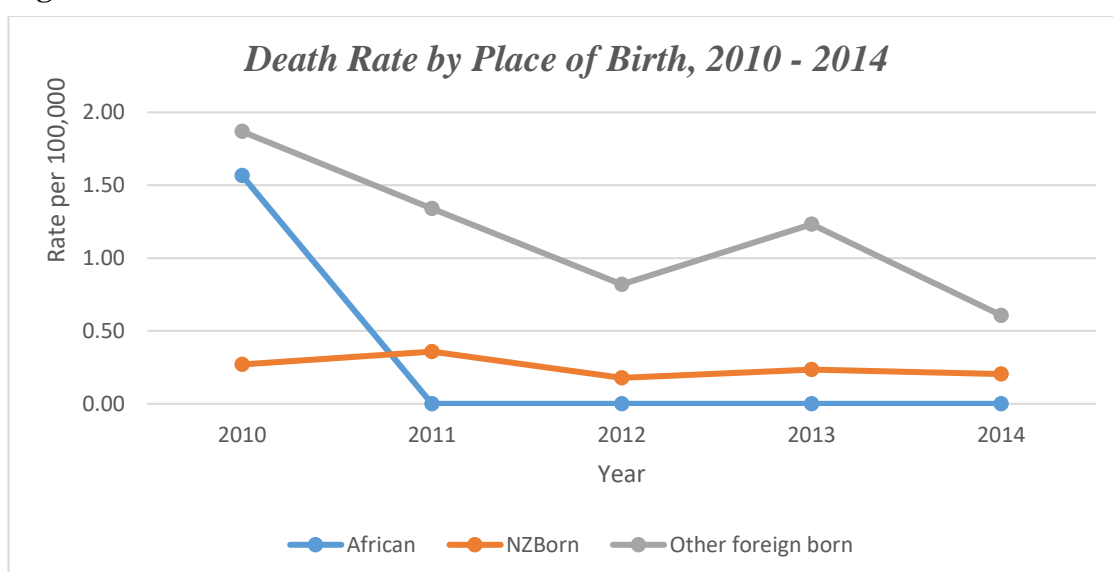
Data on deaths, as the clinical outcome, was available for 98.9% of all notified cases of TB over the study period. A total of 100 cases died representing 6.8% of all notified cases and a rate of 0.5 per 100,000 population. Deaths among males 66% (66) were higher compared to females 34% (34 cases). The highest proportion of deaths were recorded among persons 70 years and above for both males and females; 54.5% (36 cases) and 52.9% (18 cases) respectively. No case of death was reported for both males and females aged <19 years (see figure 5.16).

Figure 5.16



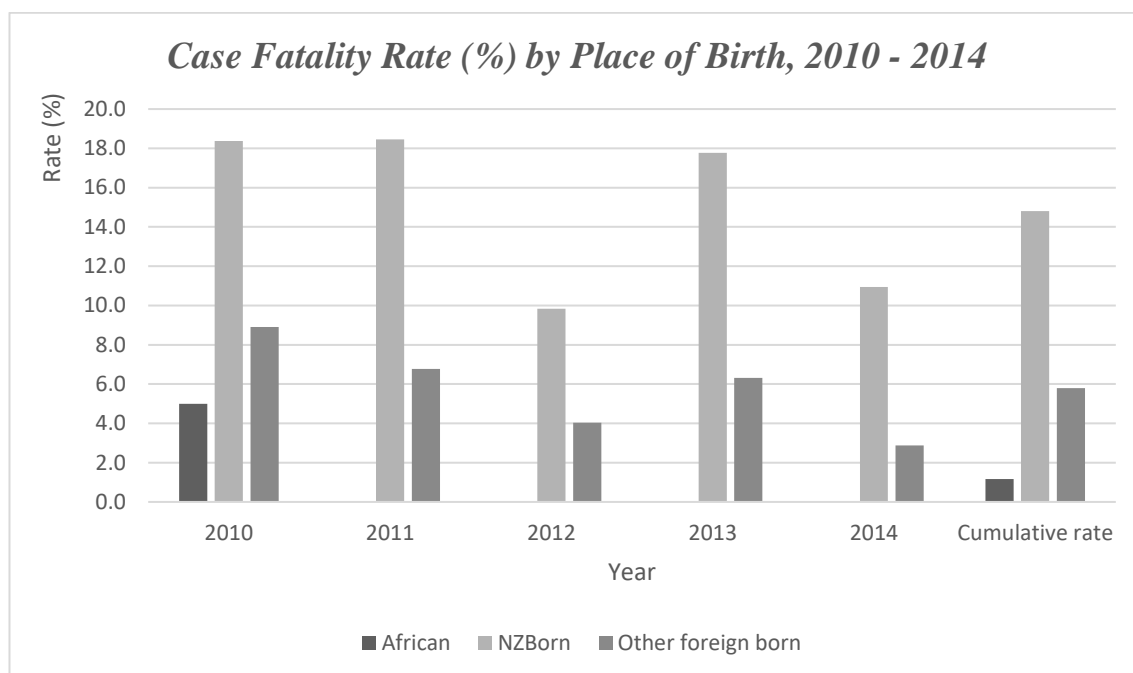
The cumulative death rate was highest among other foreign-born persons (1.2 per 100,000 population, 57 deaths) compared to NZ born (0.3 per 100,000 population 42 deaths) and Africans (0.3 per 100,000, 1 death) (see figure 5.17). Deaths due to TB declined over the period but was not statistically significant at 95% confidence among NZ born ($F(1,3) = 1.53$, $p = 0.30$) and other foreign born ($F(1,3) = 7.78$, $p = 0.07$). Among Africans one death was reported in 2010 and zero deaths from 2011 to 2014.

Figure 5.17



The case fatality rate (the proportion notified of TB who died) was highest among NZ born persons (cumulative rate = 14.8%), compared to other foreign born (5.8%) and Africans (1.2%) in all the years over the period (see figure 5.18).

Figure 5.18

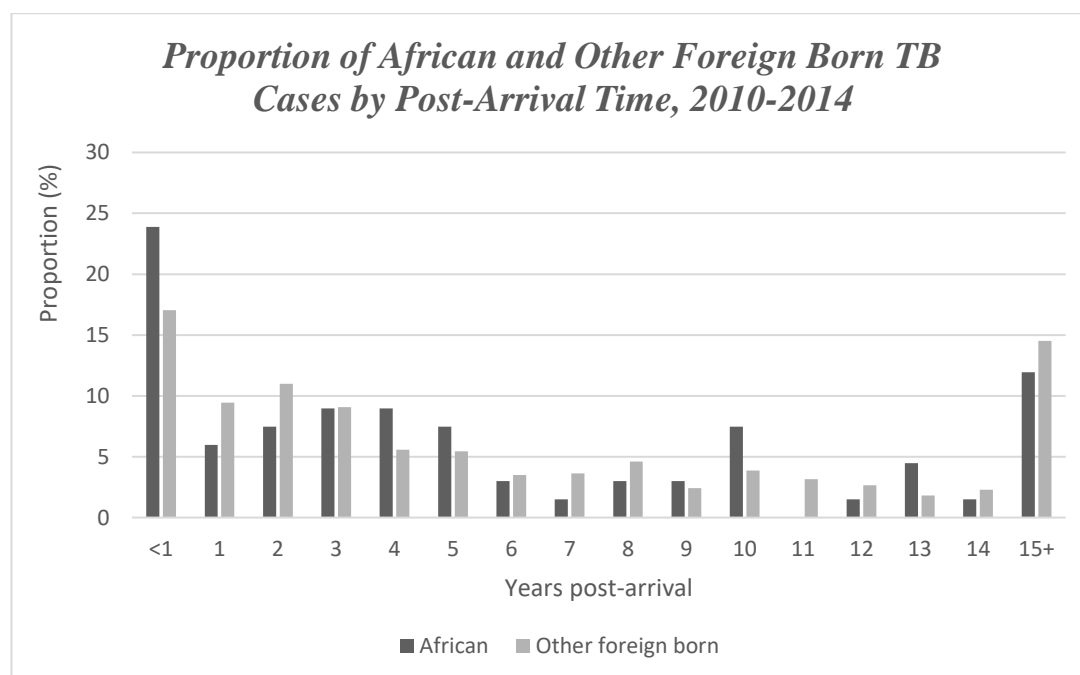


5.1.14 Post-arrival Time

Data on the year of TB notification and the year of arrival were available for 78.0% of all African and other foreign-born TB cases notified within the period. Among Africans the mean time from arrival to notification was 6.7 years and a median interval of 4.6 years, whilst that for other foreign born was 8.2 and 4.7 years respectively. The least and longest times among Africans were 11 days and 39 years respectively. Over one in five of all African cases were diagnosed within the first year of arrival (23.9%, 16 cases) and more than half of them (55.3%) within the first five years of arrival. African migrants continue to report TB cases ten years on after arrival (26.9%) (see figure 5.19). Among other foreign-born persons, notification of TB followed a similar trend, the

highest proportion of notifications were within the first year of arrival (17.0%, 141 cases), lower than among Africans, and more than half (57.6%) within the first five years post arrival. There was no statistically significant difference between the two groups in the length of time from arrival to notification ($p=0.63$).

Figure 5.19



5.1.15 Treatment

A total of 1,424 cases representing 96.3% of all TB cases notified received treatment. The proportion receiving treatment was quite similar for the three groups compared; NZ born 95.2%, other foreign born 96.7% and Africans 96.5%. Data on both onset of symptoms and start of treatment were available for 951 cases. A total of 946 (66.4%) cases were used in final analysis of the time difference after further cleaning of the data to remove incomplete and wrong dates.

The median time from the onset of symptoms of TB to the start of treatment was two months and a mean time of five months. The mean time from symptom onset to

notification was about five months and a median time of approximately 2 months, while the time difference from notification to the start of treatment was nine days on average and a median of three days.

Data were fully complete for 53 out of 83 African cases who received treatment (63.9%). Analysis focused on pulmonary TB, as any delay in treatment is a public health threat. Among Africans with pulmonary TB (23 cases with complete data), the median time from onset of TB symptoms to treatment was about three months (2.7 months) and a mean of about four months (3.7 months). About 21.7% of African pulmonary TB cases were treated within one month of onset, while 21.7% were within one to two months of onset and 13.0% between two to three months of onset, giving a total of about 56.5% of treatment initiated within the first three months of onset. The mean and median times from symptoms onset to start of treatment for other foreign-born persons were three (2.9 months) and two months (2.1) respectively, which were lower than that of Africans. Persons born in NZ showed a similar trend to that of other foreign-born persons but had a lower interval from onset of symptoms to treatment than Africans; with mean interval time of about three months (2.8 months) and median interval time of about two months (1.8 months).

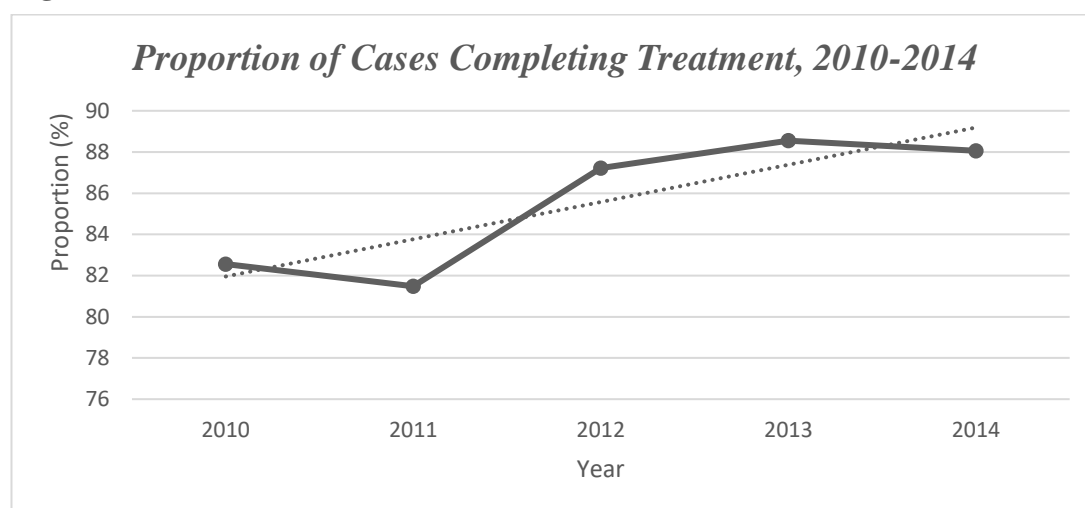
32.3% of all notified cases received DOT throughout the intensive phase of the treatment. NZ born persons (33.8%, 112 cases) commonly received DOT in the intensive phase of the treatment, more than other foreign born (32.4%, 343 cases) and Africans (25.6%, 22 cases).

5.1.16 Treatment Outcome

A total of 1217 representing 85.5% of the persons who received treatment for TB successfully completed their treatment. The proportion of successful TB treatment

completers increased by about 2% per year over the period but was statistically insignificant at 95% confidence ($F(1,3) = 8.92, p = 0.06$) (see figure 5.20). The remaining persons, who started treatment, did not complete for several reasons. The most common reason for which treatment was interrupted was death (72 cases, 5.1%), followed by persons with TB leaving for overseas (64 cases, 4.5%) and transferring overseas for medical care (28 cases, 2.0%). Other reasons leading to treatment interruption were: treatment stopped due to adverse effects (21 cases, 1.5%), refusal of persons to complete treatment (8 cases, 0.6%), reasons unknown (8 cases, 0.6%), lost to follow up (5 cases, 0.4%), and treatment stopped due to pregnancy (1 case, 0.1%).

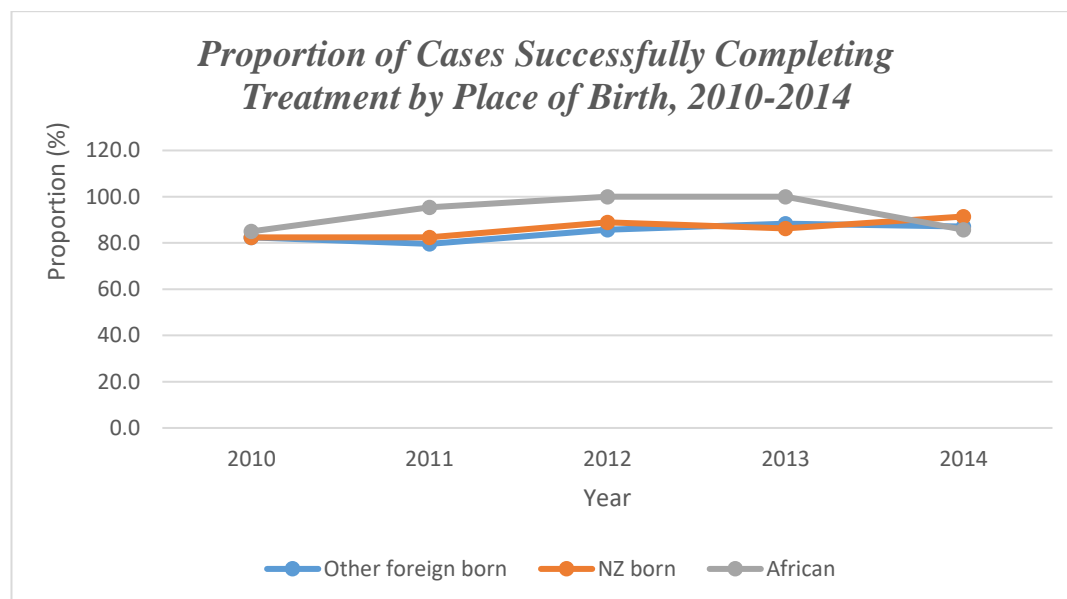
Figure 5.20



In all, 92.8% (77 cases) of Africans receiving treatment for TB successfully completed their treatment, the highest of the three groups compared to NZ born (86.3%) and other foreign born (84.6%). The proportion of treatment completers was consistently highest among Africans over the period except in 2014, where NZ born had the highest proportion of treatment completers (see figure 5.21). The proportion of successful treatment completers increased, but statistically insignificantly, over the period for all three groups compared [(Other foreign born; $F(1,3) = 5.33, p = 0.1$), (NZ born; $F(1,3) =$

9.21, $p = 0.06$), (African; $F(1,3) = 0.05$, $p = 0.84$)]. Reasons why some Africans did not complete their treatment as expected were, case lost to follow up (2 cases, 33.3%), treatment stopped due to adverse effects (2 cases, 33.3%), case transferred to overseas medical care (1 case, 16.7%) and death (1 case, 16.7%).

Figure 5.21



5.1.17 Risk factors

HIV, contact with a person with infectious TB, exposure in healthcare setting and residence in institutional settings are considered risk factors for TB in NZ. Data on whether an HIV test was performed was available for 98.2% (1452 cases) of all notified cases. Of these, 67.3% (977 cases) received testing for HIV. The proportion of TB cases getting tested for HIV increased from 2010 (63.5%) to 2014 (76.5%). Africans (80.0%) were more commonly tested for HIV than other foreign (71.1%) and NZ born (51.9%). The number of HIV-TB co-infection could not be analysed because the data on HIV status was unavailable for this study.

Contact with a person diagnosed with infectious TB is considered another risk for the transmission of TB to susceptible individuals. Of the 1,452 cases (98.2%) with available data on contacts with confirmed TB cases, 21.9% (318 cases) reported they had made contacts with confirmed TB cases. About 66.3% (205 cases) of these contacts were made in NZ. Among Africans, 21.4% (18 cases) of the cases with data on contacts, had made contacts with confirmed TB cases. Of those persons, 46.7% (7 cases) made these contacts in NZ. Persons born in NZ had the highest proportion (41.9%, 135 cases) of cases due to contacts with confirmed TB cases compared to other foreign born (15.8%, 165 cases) and Africans.

Exposure in healthcare setting was reported for 1,456 cases representing 98.4% of all cases. A total of 86 cases (5.9%) reported they were exposed to TB in a healthcare setting. Africans were most commonly exposed to TB in healthcare setting (15.5%, 13 cases) compared to other foreign (5.8%, 61 cases) and NZ born cases (3.7%, 12 cases).

Data on current or recent residence in an institution was available for 98.4% of all cases, of which 2.1% (31 cases) reported current or recent residence in an institution. NZ born had the highest proportion of cases (4.6%, 15 cases) reporting that they had or were living in an institution compared to Africans (2.4%, 2 cases) and other foreign born (1.3%, 14 cases).

5.1.18 Protective factors

BCG vaccine provides protection against severe TB disease, especially among children. 97.8% of all cases had BCG vaccination status recorded. In all, 41.4% reported having been vaccinated against TB sometime in their life prior to the onset of the disease. Other foreign-born persons (47.5%, 495 cases) more frequently reported they were vaccinated against TB than Africans (44.6%, 37 cases) and NZ born (20.6%, 66 cases).

5.2 Discussion

This is the first study to describe the epidemiology of TB among persons born in sub-Saharan Africa living in NZ. Over the study period (2010-2014), the national TB rate declined albeit statistically insignificantly. Due to the potentially long and variable time between when a person gets exposed to TB bacilli and when they actually develop TB disease, it can be difficult to make justifiable conclusions from fluctuations in the annual TB disease notifications. For example, the decline from 2012 (6.6) to 2013 (6.2) and the rise in 2014 (6.7 per 100,000 population) can be difficult to explain. Hence, trends in TB disease notifications are better explained over a period. Some reasons for the decline in African TB rate over the five-year period are offered in section 7.2. The findings showed that there were significantly more males diagnosed with TB than were females, persons aged 20-29 years recorded the highest age specific cumulative incidence rate, and that TB was commonly notified among persons living in the most deprived small areas of NZ.

The rates of TB among Africans declined albeit statistically insignificantly from 2010 to 2014, but remained disproportionately high, about 12 times more than the rate among persons born in NZ. The higher rates of TB among Africans and other foreign born is a similar trend to other countries like UK, US, Australia and Canada (Abraham et al., 2013; Public Health Agency of Canada, 2015; Public Health England, 2014; Toms et al., 2015). As indicated in chapter three, previous studies have attributed the disproportionately high rates of TB among Africans and other migrants to the reactivation of previously acquired TB infection from their home countries (Abraham et al., 2013). Exposure to TB most likely from an African source in the host country might also explain why the rates are high (Borgdorff et al., 2000; Garzelli et al., 2010). For instance, the analysis showed that seven African TB cases (8.1%) had made contacts with confirmed TB cases in NZ. While this might not be enough evidence to conclude that transmission of TB had occurred, it suggests that the risk of exposure within the African community

from an African source could occur. This assertion is supported by a previous molecular epidemiological study in NZ (Yen et al., 2013).

Africans diagnosed with TB were younger compared to other foreign and NZ born and were more commonly diagnosed within the first year of arrival than other foreign born were. This finding corroborates studies from other places (Abraham et al., 2013; Farah et al., 2005; Kempainen et al., 2001). Previous studies have suggested that most Africans diagnosed within the first year of arrival were refugees (Kempainen et al., 2001; Varkey et al., 2007). This study is unable to affirm this finding as data on immigration status was unavailable. However, about seven Africans were diagnosed within the first 100 days post arrival. These people were more likely to be refugees and would have been identified through the immigration screening at the Mangere Refugee Resettlement Centre (MRRC). Screening at the MRRC is compulsory and is a very formalised part of the arrival processes. Refugees are likely to be diagnosed with TB within the first few months of arrival because of three main reasons: stressful conditions of their travel; the conditions of their transit (refugee camps); and the resettlement process (Dhavan et al., 2017). Refugees endure harsh conditions from forced migration, as they flee wars, violence, persecution or natural disasters, with some traveling in dangerous and overcrowded conditions (Dhavan et al., 2017). The situation worsens in the refugee camps (transit points for those who reach developed countries) where many refugees live through the stress from displacement, malnutrition, poor housing and overcrowded conditions, further predisposing them to TB infections (Dhavan et al., 2017; Kempainen et al., 2001). Upon arrival in their new country, the stressful conditions of the resettlement process and the poor living conditions, such as poor housing and malnutrition, particularly within the first few months of arrival, further increases their risk of progression to TB disease or acquisition of new infection (Lonnroth et al., 2017).

There were marked differences in the number of cases reported from the different sub-Saharan African countries: 70.9% of all African cases originated from three countries - South Africa, Somalia and Ethiopia. The observed pattern is likely to be due to the interplay of two factors: the high burden of TB in these countries; and the relatively high emigration from these countries to NZ. The countries reporting the highest number of TB cases have high populations compared to the other countries reporting zero or few cases. Data from Statistics New Zealand (2013) on the usual resident population by birthplace shows that the highest proportion of sub-Saharan Africans living in NZ were born in South Africa. Persons born in Somalia and Ethiopia also constitute a large proportion of the sub-Saharan population and have long established communities following their arrival in New Zealand in the early 1990s. In the case of the other sub-Saharan countries who reported zero or fewer cases, the trend may reflect their population size in New Zealand. It might not necessarily be the case that the TB burden was low in such countries, as most sub-Saharan African countries are rated as high burden TB, TB/HIV and MDR-TB countries (WHO, 2015b). It may therefore be reasonable to suggest that an increase in immigration from these countries may likely lead to an increase in the number of reported cases if the conditions in the host country remain.

The findings from the study suggest that Africans are more commonly diagnosed with extra-pulmonary TB compared to the NZ and other foreign-born population, which corroborates other previous studies (Abraham et al., 2013; Kempainen et al., 2001). Extra-pulmonary TB, except laryngeal TB, is considered less important to public health as it is rarely infectious. However, extra-pulmonary TB, like any other disease, can lead to severe suffering and can be difficult to diagnose (Crofton et al., 1999). This finding has important implications for clinical practice, as health professionals who deliver healthcare services to Africans may need to suspect extra-pulmonary TB especially in instances where they

present with symptoms and signs that are unexplained but likely to be due to extra-pulmonary TB.

Another important finding was that 20% of all Africans diagnosed with TB were unemployed, about 30% of these people lived in the most deprived 20% of the small areas in NZ, and were most commonly (23.9%) diagnosed of TB within the first year of arrival. This supports the hypothesis that, although most Africans might be exposed to TB before their arrival, the conditions of their transitioning into their new environments within their first few years of entry may influence the reactivation of latent TB (Abraham et al., 2013; Lönnroth et al., 2009). Further discussion on how these other factors within the host country might contribute to TB is presented in the subsequent chapters of this thesis.

Africans over the period did not record any case of MDR-TB. All 16 cases reported over the period were other foreign born. A similar finding has been shown in the US where the MDR-TB has been shown to be less reported among Africans compared to other foreign born (Abraham et al., 2013). That notwithstanding, an increasing trend in the incidence of MDR TB in the African region could mean cases might be reported by persons of African origin in the years ahead (WHO, 2016). However, with the findings suggesting a high treatment completion rate (92.7%) among Africans, it may be reasonable to suggest that the trend of no MDR TB case might be sustained; or if there were to be any cases, they would be very few.

Early initiation of treatment for pulmonary TB is important for public health to prevent the chances of transmitting TB to other susceptible individuals. The median time from onset to treatment among Africans was about 3 months (2.7 months), which was higher than other foreign (2.1 months) and NZ born (1.8 months). Previous studies in NZ have attributed delays in seeking treatment to personal and health system factors (Calder, Gao, & Simmons, 2000). Lack of awareness of the symptoms of TB, fear on the part of

persons to find out about the disease, and the idea that the symptoms may go away were some of the reasons why people delayed in seeking treatment (Calder, Gao, & Simmons, 2000). Among Africans, another important factor contributing to the delays might be the stigma associated with TB. This is discussed in detail in the proceeding chapters.

5.2.1 Limitations

The limitations of the study are those associated with the EpiSurv TB data. Despite existing mechanisms to improve sensitivity and completeness of TB data (Das, Baker, & Calder, 2006), this study is limited by incomplete data entry. For instance, among cases of sub-Saharan African origin, data on treatment and year of notification, and the year of arrival were incomplete for 30 cases (36.1%) and 19 cases (22.1%) respectively.

Another limitation is the use of place of birth from the census as the denominator in the analysis. This assumes that persons born in sub-Saharan Africa may self-identify as such and the capture of TB cases at the hospital level may accurately record this in EpiSurv. This variable was chosen over ethnicity, given the inherent limitations with the capture of ethnicity data. It was observed that some African countries such as South Africa and Zimbabwe were coded as European and hence leading to serious undercounts of persons who may self-identify as belonging to the African ethnicity.

5.3 Summary

This chapter has presented the descriptive epidemiology of TB among Africans in comparison to other foreign and local born populations in NZ. Within the period, there was a slight decline in TB incidence among all the groups compared. Africans notified of TB were more likely to be male, unemployed, within their first year of arrival, in their most productive ages (between 20-49 years), from the most deprived 20% of small areas

in NZ, and more likely to originate from South Africa, Somalia or Ethiopia. While Africans with TB were more likely to delay in seeking treatment, they were the most likely to successfully complete. This chapter provided the background understanding of the African migrant TB epidemiology by establishing the most likely factors associated with TB. These factors will be further explored through semi structured interviews with study participants in the next chapter to understand how they may influence the incidence of TB.

Chapter Six – Phase II: Qualitative Results

6.0 Introduction

This chapter builds on the preceding one to present an in-depth understanding of the factors that influence TB incidence among Africans. In answering the second research question, what factors contribute to the relatively high TB rates among Africans, five main broad clusters were focused on. These are integration/ resettlement in New Zealand, economic, individual, social, and structural determinants. Under each category or cluster of interest, various main themes and sub-themes were identified. These are presented in this section, with each describing the factors that impact TB epidemiology among the African community.

6.1 Integration/ Resettlement in New Zealand

One of the main clusters identified within the data was the participants' perception about living in NZ and how it impacted their health. This cluster related to community leaders' perception about the challenges of the process of integration into a new country and the perceived differences in the living conditions between NZ and Africa.

6.1.1 Settlement Process Challenges

The transitional process of migrating to a new country and re-establishing oneself is daunting and stressful for most migrants (Berry, 1997). For many, this period remains critical in determining their future health and wellbeing.

During the conversations with community leaders it was evident that they believed most Africans do settle well in NZ:

“I can say in general they do settle well” (CL04)

“They’re settled in New Zealand as appropriate but they’ve got so much to think of especially in terms of settling themselves to be stable financially, that’s one thing for the majority of New Zealand Africans” (CL03)

Inherent in the texts above is the perception that most Africans adapted well to their new environment amidst several challenges along with the settlement process. Thoughts of becoming financially stable was considered an important issue for many Africans and one that captures the notion that Africans might still struggle years on after arrival.

One major challenge mentioned throughout the discussions with community leaders was finding employment. Most participants believed that finding a job in NZ could be difficult for migrants especially within the first few years of arrival:

“Employment is a big challenge for migrants, worse for refugees”. (CL02).

Participants particularly emphasised the difficulties in getting employed within the first few months to a year of arrival, a condition which could be worse for refugees’ due to challenges with employability. Among professionals and others with higher educational degrees, it was difficult for them to find jobs in relevant industries or sectors that matched their qualifications and years of working experience. In most cases their professional overseas degrees were not recognised in NZ:

“What I’ve discovered in settling in New Zealand is to do with employment. A lot of people who’re professionals they resoughted to what they call D3 jobs, which is basically dirty, difficult and demeaning. For example, before I came when I was in Zimbabwe I was an executive manager but my very first job in New Zealand I was a toilet cleaner of all jobs, nobody wanted to employ me”. (CL02)

The above extract describes a common occurrence within the African migrant community, where professionals such as doctors, nurses, lecturers, and accountants have resoughted to doing unskilled and odd jobs to secure some income and to survive. The story of the leader above captured the sacrifices many skilled migrants might have to endure in their quest to survive in a new country. The text alludes to the difficult nature of the unskilled jobs, which can impact the physical health of migrants. Doing such jobs

have consequences on the psychological wellbeing of migrants as well. They are demeaning, according to the leader, and could lead to loss of self-esteem or self-worth as one's previous status may be lost, constricting migrants to self-doubt and to the periphery of their new society.

The leaders believed that employment was an important factor in determining the health and wellbeing of individuals and contributed to new migrants' vulnerability to diseases, including TB. They further noted that resorting to low skilled and low paid jobs for survival by highly skilled professionals and other highly qualified persons could lead to depression:

“If you don't have a job you're not able to fend for your family and also if you're a professional and you have a job that is just an ordinary job that is divorced from your qualifications and expertise it brings depression. It brings a lot of unhappiness”. (CL02)

The text above emphasises the economic and psychosocial benefits of employment. It highlights the direct impact of employment on income and accessibility to basic human needs, while stressing the other benefits of employment to the wellbeing of individuals such as boosting self-esteem, reducing the risk of depression and happiness.

Community leaders also discussed language as another important challenge in the integration/settlement process. They recounted many difficulties faced by some Africans, especially those from Francophone countries and some refugees, with limited proficiency in the English language. Poor communication was said to inhibit their interactions with people in their new society and created difficulties in finding jobs, accommodation, seeking healthcare and other services:

“The most difficult thing for people settling in is language because most of the clients that I do work with are not from the English speaking background so when they arrive in NZ they've to study English before they can even get a job and also even if they sick to go and see their doctor, they've to with an interpreter and some of the sickness or diseases are very confidential that they prefer not to let their

own community person or interpreter to get to know the type of sickness or disease that they are suffering from". (CL03)

This community leader who works in the health and social services sector explained the difficulties some new migrants from Africa go through. They might need to enrol in English courses before seeking employment, which usually could take between six months to one year. He indicated that during this period of studying and waiting for employment, some new migrants suffered in terms of mental health. He explained that this could be due to frustrations from the difficulties in navigating the bureaucratic support systems in NZ and the financial challenges faced as a new migrant. Refugees, he explained further, lived on low wages provided by the government and from which they needed to feed, clothe, rent and remit families back home. He also highlighted that the need to use an interpreter for those with language difficulties when seeking medical treatment, led to privacy concerns for new migrants. These privacy concerns were heightened particularly for stigmatised conditions, as they would not want their medical conditions to be known to people other than the clinicians.

Within the conversation with the leaders about the process of settlement for new Africans in NZ, there was a sense of a lack of awareness about available health and social services among their community members. According to the leaders, many new members of the African community were unaware of existing support services and, in most cases, would not seek help from appropriate agencies. They unanimously attributed this to the non-existence of a comprehensive orientation/introduction of new African migrants into their new home country. The new migrants relied on the previous experiences and knowledge of other family members and friends about the available services, which were sometimes inaccurate. For those who were aware of services, lack of knowledge on how to access them, language issues or the self confidence in themselves to access these services prevented them from doing so:

“What they find a little difficult is they don’t know where services are and they don’t know how to access some services”. (CL01)

“Most of them don’t speak English very well and for that they try to limit themselves in terms of interacting or looking for where to go and seek the support so it has been difficult for many Africans and with that comes how to find employment, how to find housing and better places and things like that”. (CL03)

According to the leaders, challenges such as those described so far, have the potential to impact people’s vulnerability to acquiring TB. This perspective was corroborated by the health professionals who explained that the chances of developing TB among migrants was higher within the first few years of arrival in NZ. This pattern, they believed, was similar to other low TB incidence countries, and was likely to be due to the stress associated with the transitioning processes into an entirely new routine of daily living, and in meeting the demands of the new society. These demands, they mentioned, included finding jobs, paying weekly rent, driving, raising a family, sending remittances back home, dealing with the change in weather conditions, and finding one’s preferred food, all of which could be daunting for some Africans in the early years:

“The first two years after a migrant arrives in New Zealand is the most vulnerable time for the TB recurrence and that must be in my view a lot to do with stress and with the attack on the immune system that stress causes, and I mean that’s a whole multi-layered issue but you know, getting housing, and getting employment and getting people into work in the area that they’re skilled at is hugely important for the psychosocial as well as the economic well-being and I don’t think we do particularly well” (HP01)

This health professional emphasised how TB infection, which might have been acquired in a previous country, was likely to be reactivated due to the range of stressors associated with the process of settling in their new country and the attack of that stress on the immune system this could create.

The challenges associated with settling may not be peculiar to the African community. However, this community may require more support in the process of adapting to their new environment due to their complex health needs resulting from

previous experiences in their home countries, as in the case of TB. Community leaders suggested that a comprehensive and structured approach to supporting their members through the transition process could help them integrate better in their new environment and minimise the risks of developing health conditions within their early years of arrival. As one leader puts it:

“We need a better introduction to live here” (CL01).

There was great dissatisfaction among community leaders about the current processes for settling their community members. Their frustration was borne out of the belief that the initial process of settling was the most important point in determining the health and wellbeing of their people, but was something that had attracted less attention from the public officials.

6.1.2 NZ/Africa Seen as Different

This theme was identified inductively from reading the interview transcripts. It was clear from the conversations with community leaders that, along with the difficulties in integrating into their new society, living in NZ was deemed very different for most Africans:

“The lifestyle is very different” (CL01)

The above quote was from a community leader who has been living in NZ for over 28 years, with all other leaders expressing similar views. They believed there were major differences in lifestyles between NZ and Africa and this could create difficulties for African migrants (and in particular for recent arrivals):

“I think what I found that is different is actually the cultures, the way of doing things, the processes that can be quite daunting if you’re coming from Africa”. (CL01)

The leaders positioned NZ and African cultures and processes to be quite distinct and suggested that navigating this new society in search for support or services such as healthcare, accommodation, or school for kids could be ‘daunting’.

Although different to Africa, overall, the participants seemed to prefer the organisation of the NZ society and the effectiveness of institutions in the delivery of services in comparison to their own countries. Some liked the democratic system of governance, which allowed them greater freedoms than they had in their own countries:

“Life is organized. I think New Zealand way is better compared to Africa. In Africa, everything is really slow but here things are fast and accurate” (CL03)

“Living in New Zealand is quite a good place, it’s safe, quiet, there is space and it’s a democratic system in which one can be involved in the decision making” (CL04)

Leaders who migrated to NZ as refugees, fleeing dictatorships and war in their countries, preferred the safety they enjoyed in NZ and the opportunity to be part of the ‘decision making’ in their new country, something they could not have done back home.

Also, overall, African community leaders were quite happy about life in NZ. They believed that life in NZ, with regards to their finances, was better compared to that in their own countries, as salaries were higher and even though it could be hard to get employment at first (as noted above), overall there were more job opportunities:

“Life can be also quite challenging for many people in Africa because what they’re getting as wages or finding job sometimes is hard and they’re getting very low wages whereas also of course people who migrate as refugees in New Zealand also find it difficult to find jobs which is similar but here in New Zealand you can still find support especially from social welfare whereas in Africa you don’t have that” (CL02)

These difficult conditions back home, they argued, could be similar to what refugees/asylum seekers and other recent migrants faced within their first few years of arrival in

NZ. The difference in such situations, they reckoned, was the availability of social welfare and other support systems in NZ, which were non-existent in their own countries:

“The social welfare and the different organizations that can support you are out there whereas in Africa it’s quite yourself especially in most countries and can talk more about Congo” (CL04)

Notwithstanding participants’ preference for the NZ way of doing things, there were some aspects of the African social life that they missed. They held the view that the strong ties and communal living in their countries of origin were beneficial for their health and better than the individual centred lifestyles in NZ. They had a strong desire to have the style of community and communal living from home, in NZ:

“In Africa, you have people living together so it’s quite easy in terms of contact with other community members, your neighbours, you can know them very well, they know you and sometimes they can offer you support in looking after your children when you go to work that is something that is quite different from New Zealand” (CL04)

The above extract captures the notion of communal living in most African countries, and highlights the benefits of the concept of interdependence and collective living. The leader above, like the others, believed the African style of living that encouraged support from neighbours and other extended family members was better. They argued that strong social networks do not exist for them in NZ, and that their existing relationships with other people outside of their families were superficial unlike what persisted in their home countries, and did not come with the benefits they were accustomed to. The break from such strong social ties through migration to their new homes could impact negatively on their health:

“From a social perspective, what I’ve experienced for my past 15 years in New Zealand is that though in New Zealand the life style is much much better in some respects but when it comes to social issues I really miss home. I would have preferred if I was in Zimbabwe because I left my family there, people who cared for me, if I got any problems I know that I’m well looked after and all my childhood friends, my parents, my community they’re all basically there” (CL02)

The extract highlights what community leaders perceived as protective factors associated with the social lifestyles from their countries, which they do not have here as much. From the conversations with the leader above, 'missing home' was a frequent occurrence for him especially in times when he needed the support of family and friends. To him, after all the years of living in NZ, collective living was one aspect that offered him much happiness and something he's yet to overcome.

The leaders underscored the value of the various African community groups as an important source of information and social engagements, which creates an opportunity for community members to socialise and to build networks of support. The leaders believed these community associations were bridging the gap between the two realities for Africans; the once communal and vibrant social lifestyle in their own countries and the now independent individual centred lifestyle.

6.2. Individual factors

This cluster was identified deductively from the application of theory in the reading of interview transcripts. Individual factors such as TB knowledge, risk perception and sources of TB information were identified as important factors that may influence TB control efforts. These factors impact an individual's ability to recognise symptoms of TB, to seek early treatment and to prevent transmission of TB infection to other susceptible persons. The African community leaders reported differences in their general knowledge of TB. They had a low perceived susceptibility of TB. They reported low awareness-raising activities of TB in their communities and suggested appropriate strategies for delivery of TB messages in their communities.

6.2.1 Mixed Knowledge about TB

The level of knowledge on the biomedical understanding of TB among participants who were community leaders was mixed. There was a high awareness of TB among the leaders, although some said they did not know what the causes of TB were:

“Personally, I don’t know specifically what causes TB. I’ve heard about TB but don’t know exactly what causes TB”. (CL03)

Within the discussion with the community leaders about TB, one participant indicated that most people coming from Africa might have been exposed to TB prior to migrating. He further explained that the stressful conditions of their living post arrival could lead to a compromised immunity, which might trigger the dormant TB to become active leading to TB disease:

“Someone who’s nutrition is not good, they’ve got stress all the time, poor housing, jobs, and they don’t have a good nutrition themselves so they can get their immunity going very low and because we come from Africa TB could be dormant at that time and the disease can show once our immunity goes down”. (CL004)

The above extract captures the existing interaction between the home and host country factors in influencing TB incidence. It demonstrates that the leader perceived the TB burden to be high in Africa, which increases the risk of exposure. It also highlights the emphasis the leader puts on living conditions and how that can increase the likelihood of developing TB especially among people who migrate from high burden countries.

The discussion about the symptoms of TB produced mixed responses. Some participants expressed ambiguity on the symptoms of TB:

“I think your respiral system something there, changes. Obviously, there must be something that they look for but I think your respiral system changes or gets affected or may be becomes like asthma kind of thing”. (CL01)

But, others were confident in identifying some of them:

“TB makes you cough” (CL03)

“...loss of weight, persistent cough and those things” (CL04)

All the leaders knew about the link between HIV and TB, and it frequently came up in the discussions:

“TB is one of those opportunistic diseases, infectious diseases that attack HIV people especially when you are at the end of your life. You know, [when] your immune is gone, TB drops in”. (CL01)

The text reflects the level of awareness on the role of HIV in TB acquisition and vice versa within the African community.

6.2.2 Low Risk Perception

Throughout the discussion, community leaders did not perceive themselves at risk of acquiring or developing TB in NZ:

“I don’t consider myself to be at risk of TB in NZ here because from what I know TB is quite common back home in Africa but in NZ TB isn’t that common compared to the rate in Africa” (CL02)

“I don’t think I’m at risk. I think one of the reasons for TB could be because of the lifestyle so you got nutrition and all that and the number of people around you with TB, so yeah, less risk because it’s low here and I don’t know how many of the people around me got TB” (CL04)

The leaders noted that TB was common in Africa not in NZ and hence they could not be at risk. They also believed their living conditions minimised their vulnerability as they had good nutrition and did not have people with TB around them. This misconception was shared by all community leaders and may reflect the general view among many Africans.

Interestingly, they all perceived TB as a disease for the poor and common in less developed countries:

“I think it’s in places where probably there is poverty and that knowing that we don’t have that kind of poverty in New Zealand that means this kind of infections are not here either, the individual Africans don’t have it” (CL01)

From the above quote, the leader seemed convinced that she could not get TB in a ‘rich’ country. For her, TB only existed in impoverished places. She believed that migrating out of her country of origin, which had high levels of ‘poverty’, to a country free from ‘that kind of poverty’ meant she was out of the trappings of the diseases of poverty such as TB. Living in NZ was perceived to offer some form of protection from infections common in less developed countries and so the leaders seemed not to be particularly worried about such diseases.

In the estimation of community leaders, the perception of risk among the African communities was low as many members of the African communities believed there was no TB in NZ:

“For a majority of them it doesn’t exist here in New Zealand because they don’t know anyone who has it or maybe they never met or never heard about TB in New Zealand”. (CL04)

“Our people, you know, most of them come here relaxed thinking there’re no such diseases here. We think in Africa is easy to get disease but here it’s not here, but disease is everywhere.” (CL01)

The leaders emphasised that many Africans after arrival in NZ believed they were safe from certain diseases, which were perceived as only prevalent in their countries. According to the participants, this notion was not different from the main stream NZ community as the majority of them believed that TB had died out. Indeed, this misconception seemed common within the African and the general NZ population. For instance, it was a frequent occurrence in my conversations with community members, both African migrants and persons of other ethnicities, to be asked if there actually were cases of TB in NZ. To many New Zealanders, TB had long been eliminated, while many migrants from high burden countries believed TB did not exist in NZ and so could not be

contracted. This observation was similar to that of one participant, a physician with several years of experience:

“I think it’s not something people think about a great deal. The fact that even when I talk to lay people often they’re very surprised that we still have TB in New Zealand. People think is something that died out” (HP04)

He believed that TB in NZ had declined to such low levels that most people might not experience someone diagnosed with TB, which is different from what existed some decades ago when TB was much more prevalent. He further explained that the sharp decline had contributed to a general societal perception that TB had died out in NZ. The low perceived vulnerability to TB could lead to, he reckoned, delays in seeking help as symptoms might be misinterpreted for something else.

6.2.3 No Awareness-raising Campaigns

Participants reported that TB was less discussed within the general NZ society as opposed to their countries of origin. According to them, there were no messages in main stream media, at health facilities, or at African community gatherings that raised awareness about TB:

“There’s a department that deals with it but you don’t hear about it on television, you don’t see it on pamphlets when you go get your public information. It’s something that’s quite hidden.” (CL01)

The leaders were convinced that TB was ‘quite hidden’ and probably not present in NZ, as there were no discussions or campaigns on television, radio or in the print media. They found this to be directly opposite to what existed in their own countries, where there were strong media and other community awareness campaigns on TB. The silence on TB strengthens their perception that TB did not exist in NZ.

The leaders believed that creating more awareness within the African communities was important in changing the perception that TB was non-existent in NZ:

“I think to create more awareness is the most important way to go”. (CL03)

They suggested the use of flyers, TB talks at community gatherings, creation of an African Hub, using already existing African community groups and TB workshops as some of the most effective strategies to be used in creating awareness on TB among the African population:

“I think the most appropriate will be to print a flyer or brochure with that information on TB. So, when there’s any community gathering like Ghana independence or Ghana, Nigerian or any African gathering then that person can set up a stall or small table and distribute flyers. Also, if there’s any African gathering you can talk to the community leader and they can give you five minutes so that you can talk to them about it” (CL03)

From the extract, the leader indicated that there was the need to widely disseminate TB messages at any available opportunity. In addition to the messages, the leaders believed that Africans needed more recognition, and to be actively engaged by the Ministry of health in designing health interventions for members of their communities:

“We need hubs, so that we treat ourselves or we have the government or the Ministry of Health actually recognise there are people, African community, that are eligible to take over their own health and help their community and once they put together we label a hub, we don’t have a hub, we are very segregated so how do I put information to my people” (CL01)

Within this extract, the leader alluded to the seeming disunity among the Africans living in NZ. She believed the segregation within the African communities made it difficult to reach them with health messages. The proposal to create a hub was intended to offer a one stop shop for the coordination of all African interventions. This idea, as the leader mentioned, would help in getting the needed recognition from Government and to get Africans involved in dealing with matters of concern to them.

6.3 Social Factors

Participants shared their opinion on how social factors impacted the health of African communities. Community leaders' views formed the most part of this cluster, and were confirmed by health professionals. The analysis identified community perception about TB, stigma and discrimination, and support systems as important social factors that influence TB epidemiology.

6.3.1 High Awareness of TB as a Disease among Africans

Participants generally perceived community awareness of TB to be high and linked that to their previous experiences from their home countries, but had doubts about their biomedical knowledge on TB:

"I'll say may be about 90% of Africans living in NZ know about TB because most of us were born in Africa so one way or the other we have a family friend or a close friend that has had TB before so we've heard about it but we don't really know about the causes of it". (CL03)

The leader in the extract above noted that most Africans would have heard of TB or might have experiences with people diagnosed with TB in their countries before migrating. While the level of awareness was high, he was uncertain about their knowledge level on TB, which was considered important in identifying TB symptoms for early diagnosis and treatment. His perceptions were shared by other leaders:

"I think they've heard of it. They are aware that TB exists some might even have the knowledge of someone with TB". (CL01)

The leaders believed that Africans who migrated 'a little bit older' were more likely to be aware of TB:

"I'll like to believe that those who came from Africa a little bit older in age, may be 15 and above, they're aware of TB, they know the causes" (CL02).

This belief was on the assumption that persons at lower ages might not have experienced or understood TB well enough before migrating. In his estimation, general knowledge on TB was relatively higher in most African countries than in New Zealand, hence Africans living in NZ were likely to be less knowledgeable compared to those back home:

“Generally, if you compare the Africans for example in New Zealand and the Africans back home those back home are more knowledgeable on TB than those who are domiciled in New Zealand” (CL02)

The leader seemed to suggest that, while TB was a priority disease for most African countries, with several community sensitization campaigns aimed at raising awareness, this was not seen as the case in New Zealand.

6.3.2 Uneven Community Treatment of People with TB

Generally, the responses to how persons with TB were treated by the community were mixed. Some participants believed that, given the culture of Africans, persons with TB would more likely be treated and supported well, but emphasised that that would be achieved with some community education on TB:

“We as Africans come from a culture of respecting, we’ve been groomed and raised up in an atmosphere whereby I’ve to look after my own brother or a member of the community so I’ll like to believe they’ll be a lot of support from the nuclear family and also within the extended family but that means a bit of education, you know, on the part of the communities”. (CL02)

This leader believed that the African culture of interdependence, which forms an important part of the African identity, meant most Africans were more likely to offer support to persons with TB. He further mentioned that there was the need to educate the community on TB as the lack of understanding of the causes, transmission and prevention of TB might prevent people from genuinely offering support in the light of their cultural position.

Other participants thought persons with TB were isolated because people feared they would get TB through their contact with them:

“For TB, I think people will isolate themselves from getting closer to the person because they know that if the person coughs or sneezes there’s chance that you might get the TB so I think if somebody gets TB within our community I think the person will not find it easy because the close friends and the family members will isolate themselves from the person” (CL03)

The above extract captures the sense of fear associated with TB – a dreaded disease that must be avoided. The leader perceived TB as a severe disease that is easily transmitted from contact with infected individuals. While this perception may not be entirely true, it contributes significantly to the choices of community members in their interactions with persons with TB as highlighted by the leader.

6.3.3 Stigma and Discrimination

Stigma was repeatedly mentioned by participants as a key social factor influencing the epidemiology of TB among the African communities.

6.3.3.1 The drivers of stigma

Most participants explained that TB was hidden within the African community. It was not frequently spoken about and persons with TB were more likely not to disclose to other family members due to the fear of stigmatisation and isolation. Participants also believed that most people with symptoms of TB were more likely not to own up:

“If somebody owns up and go for the treatment it means his or her close friends will isolate themselves from him or her” (CL03)

“This is certainly from what I’ve seen from the refugees from African backgrounds, having TB is deeply hidden not just from community members but from other family as well” (HP03)

From her several years of service, this public health nurse believed that persons of African descent with TB often hid their disease from other family members. The perception that people might isolate themselves once they find out and the shame that comes along pushes persons with TB to conceal their disease.

Participants mentioned that another reason why TB was concealed within the community was the sense of negative labelling and stereotyping by the dominant cultures, which contributes to the denial of the existence of such health issues like TB:

“I think too it’s linked to, as a saying, that sense of being picked on, you know, because I’m an African therefore I’ll have TB and I’m vulnerable to have HIV and every other disease. So, I think there’s a sense of westerners labelling as well”. (HP01)

This health professional emphasised that the feeling of being labelled by other dominant groups as the people with TB, HIV and other diseases might push Africans to conceal such diseases to reject the label. She further explained that such stereotyping of population groups negatively impacts public health goals.

The participants explained that the feeling of shame associated with TB and the expectation that others might discriminate against them once they found out stopped persons with TB from talking about their disease, and was not only common among Africans. People in general, regardless of their ethnicity, were uncomfortable finding out that they have TB:

“Recently we diagnosed TB in a doctor he was of European decent and I remember that person was very upset when they were diagnosed not so much about having TB or worried about the treatment but was very worried about the effect it might have on the staff members where they worked if they found out”. (HP04)

In sharing this story, this participant emphasised that most persons diagnosed with TB frequently faced the challenge of dealing with the notion that they might have passed the disease on to other people unknowingly. They become more concerned about what others

might think of them when they find out about their disease. He further explained that this self-imposed feeling of guilt and shame was somewhat pronounced among persons from close-knit communities such as the African communities.

The strong perception that TB is linked with HIV, and that HIV is the underlying cause of TB within the African communities influences the high stigma associated with TB and the stress on individuals to conceal their diagnosis:

“TB is getting closer to HIV, you know. It’s the same level that we Africans consider TB even though we know TB can be cured but HIV cannot be cured but still people are too scared contracting that disease”. (CL03)

“The link with HIV and TB in Africa perhaps that’s part of that because in sub-Saharan Africa probably 40-50% of all TB cases have HIV so I think the stigma of HIV and TB together making a huge and even bigger stigma because of what people know from their country of origin perhaps”. (HP02)

From the participants’ above, most Africans feared acquiring TB because it was regarded ‘at the same level’ as HIV. They further explained that previous experiences of TB and HIV as a deadly disease and the negative impact most Africans might have witnessed in their own countries might lead some to discriminate against persons with TB. They would simply want to avoid it.

6.3.3.2 Experiences of discrimination

Within the interviews, it was mentioned that some Africans with TB had experienced some form of discrimination. Some participants expressed concerns over the discrimination that some persons living with TB or HIV had faced from their employers:

“I’ve known some cases whereby people have been stigmatised by ignorant and unscrupulous employers and employees and some have actually resigned and some whom I know have actually gone back to Africa which is very very sad”. (CL02)

This leader highlighted the discrimination some persons living with TB/HIV faced. He explained that there were many other reported incidents of discrimination by what he

described as ‘unscrupulous employers’, while several others suffered in silence unknown to the public authorities out of fear or lack of knowledge about where to report.

According to some participants, persons with TB were sometimes discriminated or felt stigmatised even at healthcare facilities where one would least expect this sought of treatment:

“we’ve to make sure that people are not stigmatised, but occasionally you get people even in the hospital system, an admin person not a doctor or a nurse but an admin person who might have an attitude”. (HP03)

This participant positioned the hospital system as one that should be free from any form of stigma or feeling of discrimination against any person, but admitted that there were instances where such incidents did occur. She added that there were systems to check such forms of negative attitudes of staff, which had the potential to stop people from seeking healthcare services.

6.3.3.3 Stigma as a barrier to accessing services

The participants believed that stigma was a key barrier to TB services. They all agreed that stigma could prevent persons with symptoms of TB from seeking services:

“There is stigma associated with TB and if they don’t know where to go it’s gonna be hard for them to go to someone who may know where to get support. Also, they may try not to do it if they’ve to see their GP or go further from there knowing that if I go and if that’s the situation may be people will know that I got TB”. (CL04)

The notion that persons with TB might not be comfortable asking others for help was often mentioned. This leader believed most would avoid discussing their symptoms even when they needed help, and might abandon attending the hospital for further TB confirmatory tests once referred by their GPs due to the shame that the diagnosis would impose on them.

The participants further explained that the stigma associated with TB was a barrier to the delivery of TB services by healthcare workers:

“Stigma is always an issue with TB, we still get clients who don’t even want the people they’re living with in the same house who may or may not be their family to know that they’ve got TB so that’s quite tricky because they usually know they’ve been at the hospital, they know they’ve been sick, we’ve to follow them up if they’ve got infectious TB so sometimes we’re in this weird position of following up flat mates say of someone who doesn’t want flatmates to know that is them that has the TB”. (HP01)

This health professional intimated that TB stigma was pervasive and an important barrier to the delivery of care. The social dimensions of treatment for TB would require support of families and friends. However, the high levels of stigma, she believed, limited the support individuals could derive from their networks and prevented healthcare providers from effectively delivering care, which might include soliciting support from families or close relatives. Such stigma also affected other public health activities:

“Sometimes there’ve been barriers to offering testing to contacts particularly some communities where there’s some stigma or defensiveness around TB. So paradoxically I suppose public health trying to help and make sure people don’t develop or have TB but find it difficult sometimes to access some communities if the relatives, friends or the people around the index case sought of close up saying there’s none of us here who’s got TB, we don’t want people testing us for TB, some people react as if they don’t want to know”. (HP04)

The health professionals, from the extracts above, discussed the difficulties they encountered in dealing with persons with TB, especially ones from communities with high levels of public stigma against TB. The challenges, as they explained, ranged from when professionals needed to do contact tracing to find other persons who might be exposed to the person with TB, to when public health nurses needed to do treatment follow ups. It was clear from the conversations that, while health professionals were much concerned about protecting the health of persons with TB and the public, persons who had been diagnosed might be more worried about ways to keep their diagnosis secret from other members of their community including, sometimes, their family members, flatmates

and co-workers. This, the health professionals believed, could inhibit their efforts to provide effective TB care.

6.3.4 Social Isolation

During the interviews, some participants noted that persons with TB had to live through some level of isolation. They believed that the characteristics of TB itself engenders the isolation, beginning from when a person with infectious TB is admitted at the hospital where they were separated from family and acquaintances:

“Being in a single room is quite isolating” (HP04)

“That isolation alone tells you you’re no longer a human, you’re but you not, you know that, that’s why you are isolated”. (CL01)

The above extracts highlight the physical isolation endured by persons with infectious TB. The participants explained that the use of physical barriers such as nose masks by the healthcare professionals attending to them in the hospital and the length of time spent in the isolation room alone made persons with TB feel separated and different from others.

At the community level, the notion that members might gossip about them once they found out about their disease state pushes them to suppress the symptoms of the disease and as in most cases withdraw themselves from the community:

“TB can be quite an isolating disease, so if you’re in the hospital you’re physically in isolation if you’re infectious, so there’s physical isolation, and there’s social isolation and then the stress for people not to know that they’ve got TB so that they’re not culturally isolated by people who don’t understand that actually they’re not a threat to anyone and could be completely cured and that TB is okay”. (HP03)

The extract above was corroborated by a community leader who explained that, in an attempt to hide TB from other community members, most persons with TB withdrew themselves from the larger group. Such persons remained isolated and cut out from the

support they could have enjoyed from the community, especially, in instances where there were no immediate family members to offer them support throughout their treatment:

“If someone knows from the community they may gossip about it or they may just try to withdraw themselves and that person can find themselves isolated if they don’t have anyone as family to support them at least morally or psychologically”. (CL04)

6.3.5 Social Support

Most community leaders were not aware of any organized social support for people with TB. One community leader who is an HIV advocate, mentioned the benefits one receives from such social support groups in HIV treatment and explained how that can help persons with TB

“If there’s a support group you find that makes it easier for people to live with the disease...there isn’t as far as I’m concerned there isn’t a public support group that we all know of like we do have for breast cancer”. (CL01)

This leader believed that there were no public support groups for TB as there were for other diseases such as HIV and breast cancer. The availability of such support groups, she reckoned, could be helpful in supporting persons with TB through their treatment. Again, she believed that a high awareness about existing support facilities for persons with TB could help minimise the fear associated with acquiring TB, as getting diagnosed might not be a burden for just one person but one shared by other persons and even organizations.

When asked about the availability of community support, there were mixed reactions from community leaders. Some of them opined that there were weak support systems for Africans living in NZ with most Africans surviving by themselves without much support from their communities:

“We don’t have the support system and most of us Africans we don’t because we came here either by our husbands or join family and then you get diagnosed with this kind of disease, you know, and we’re all by ourselves”. (CL01)

Others believed that the African communities offered a network of support for their members. According to them, they served as the source of information on jobs, education and other opportunities for members. In some instances, they offered material and financial support to members under distress conditions:

“In terms of social support, I can say most of Africans, majority of them are well supported by their own community, the community functioning quite well, their interaction is quite well”. (CL04)

6.4 Economic Factors

This cluster relates to participants’ description of the financial and living conditions of Africans in NZ. The discussions centred around two themes: the living conditions of Africans; and the costs associated with TB.

6.4.1 Poor Living Conditions

Community leaders believed that, while the financial and general living conditions of Africans were quite acceptable, the majority of them had a low socioeconomic status. For the many who lived on low wages, life was a challenge and a struggle to survive daily. They explained that a low income affected the health of people as it determined what people could afford to eat, where to live, their level of education and their ability to seek medical services:

“I’ll say may be 60% of Africans living in NZ are on low income and the households in which they live, like a three-bed room house will have about eight or nine people living in the house and most of the houses are housing NZ so it’s very damp and cold houses and also the food that most of them eat are oily and

fatty and yeah so economic wise I think the standards of living for Africans are very low, yeah they're very poor in NZ". (CL03)

As a social worker who deals with African social support issues, the leader above seemed convinced, based on his observations, that the standard of living of most Africans was low. He recounted instances where people have had to live in overcrowded conditions due to their inability to pay the high rents for decent homes.

According to the leaders, the poverty experienced by some Africans was in part due to the lack of information on the social support services available, the skills needed to access these services and to compete in the new society. All participants agreed that poverty was an important contributor to TB. One of the participants, with several years of experience working for an organization that provides support for people living with TB in Auckland, stated:

"TB generally attacks people who live in cold damp houses which often communities who're financially challenged tend to be living in. Poorer accommodation with poor heating and poor curtains. So, we try and make sure the environment is not going to damage people's health and it's going to enable them to get well. I know that we've given quite few heaters to African people over the years, I'm just thinking of some people I've given to in the last year or two, because often they live in a mouldy accommodation with poor ventilation, poor insulation, and no proper heating". (SO01)

This participant enumerated some risk factors that were common for persons with TB who required support from her organization, and explained how poverty contributed to such mediating factors. Within the text was the idea that 'cold damp houses' might be contributing to TB in NZ, as most of her clients lived in poorly ventilated and uninsulated homes, which explained why the largest support offered by her organisation to families with TB were heating accessories.

Other participants shared similar opinions and were convinced that many of the persons diagnosed with TB belonged to the lower socioeconomic levels and so struggled to pay rent, power, phone and food. The pressure on family income increased with the

rising cost of housing and rent. Accordingly, participants noted that the current poor housing, overcrowding and homelessness situation in Auckland was likely to influence the rise in individuals' vulnerability to the acquisition of TB and other infectious diseases. One participant, a health care professional, who works for migrant communities, further explained this citing the example of a Marae in Mangere a suburb of Auckland, Te Puea Memorial Marae, which opened its doors to homeless people on July 25, 2016:

"A lot of that has to do with the determinants of health and I am deeply disturbed by the housing situation, homelessness and I don't know if you've seen that a Marae in Mangere opened its door to homeless people and some of the people who turned up there were from refugee backgrounds". (HP01)

She believed that the poor circumstances under which most migrants lived contributed to their vulnerabilities to TB. For her, the housing situation was critical and one that exposed refugees to the reactivation of infectious diseases that they might have contracted in their countries or in refugee camps pre-arrival.

From the discussions was the notion that TB had the potential to worsen the living conditions of persons already living under distressed conditions. Participants mentioned that financial issues that go along with TB treatment places a huge burden on families that were already financially challenged and struggling. Although some financial and material support may be available for people on TB treatment, sometimes pride prevented them from accessing such:

"It's not an easy thing especially saying I need financial help. I do think sometimes people try to cover it and look like they're doing okay but they're not". (SO01).

While the impact of TB on financially constrained families was dire and so needed some support, it was identified that pride could force them to 'try to cover up'. In some cases, persons on treatment insisted on supporting themselves even when it was obvious they needed help.

6.4.2 Costs Associated with TB

The analysis showed that TB had implications on the economic conditions of people. From participants' recounts, there were direct costs for persons diagnosed with TB, their immediate families living in New Zealand and the ones back home. TB also had a social cost to people, as social ties might be cut to conceal the disease from close relatives and the community.

The study found that community leaders were aware that TB treatment was free:

"All I know is treatment cost of TB is free at the hospital so if you get to the hospital then the treatment is free". (CL03)

The cost of TB drugs is free, so are the investigations to exclude or diagnose TB as soon as someone is suspected, and that of hospitalization if required. However, the cost of other non-TB drugs, which a doctor might prescribe as necessary for a person with TB would have to be paid for by the person. This, the health professionals agreed, could be a burden for families that were already struggling financially:

"So, the doctor writes 5 items that are not TB drugs that person needs to pay for those". (HP03)

In instances where individuals were unable to pay for the additional costs, requests were made by the public health nurses to the support organization to help such individuals in paying the additional costs of medicines.

The participants explained that the costs associated with TB were not just limited to treatment. There were other aspects of a person's life that might be affected, which could negatively impact their financial circumstances:

"The cost can be huge as I said for the two cases that I know about the cost can also impact on the family because if you've TB and you can't go to work then there's economical cost with the family, who's gonna feed them plus who's gonna pay for the rent if they're renting and even if they own a house there's a mortgage that you need to pay and everyday costs so food and other expenses". (CL04)

This leader stated that TB impacted employment of individuals, which could lead to challenges with family incomes. Drop in income, he explained, could affect feeding, renting and other living expenses for persons with TB. The impact of TB on employment was further highlighted by participants. One of the health professionals, a physician, explained that hospital isolation might lead to loss of income for some individuals:

“I think in many if not most of the people with TB if they’re infectious they’ve to stay for two weeks for their treatment. Some if they’re highly infectious will have to stay for up to six weeks and I think we get problems with their loss of income”. (HP04)

This participant mentioned that in instances where a person had to stay off work because of TB while still infectious, they were likely to lose their jobs especially if they were in a casual job. Persons who were in full time jobs were more likely to be retained after treatment by their employers sometimes with the intervention of health professionals.

Participants could not directly show how TB might impact a person’s ability to gain employment several months or year(s) after treatment. However, some shared their experiences with persons who were cured of TB and had lost their jobs. They explained that some of these persons had lost their jobs because some employers, due to fear of another episode of TB or the stigma associated with TB, would not want to re-employ them. On the part of persons with TB, they might decide not to return due to the feeling of shame or guilt associated with TB. The latter was identified as a challenge for persons with TB to get back to the workforce given that they had not worked for a while. Again, they might not possess the needed or transferable skills required to find the right job that might be different from the previous:

“I know three people who had TB before but even after, you know, like they spent a lot of time at the hospital and when they came back from the hospital the employers did not tell them that because of the TB, but they just said to them because you spent a lot of time from work your position has been offered to another person. But the person thought it wasn’t the position which had been

offered to another person because that person talked to his colleagues and found out that there was no new worker working there, but because of the sickness the boss tried to find different ways to kick him out from his work place". (CL03)

Within the extract is the notion that TB can have a negative impact on people during and after treatment. It captures the sense that TB can deny people their source of livelihood and, in some cases, may push them to start new roles or careers in industries or areas of work not familiar to them. In instances where persons with TB, due to their visa status, are ineligible for any government benefits the consequences can be catastrophic during the period of job search.

6.5 Structural Factors

This cluster relates to the TB and health service delivery factors, policies and other environmental factors that influence the accessibility and delivery of TB services. These factors have a direct impact on TB prevention, diagnosis and successful treatment.

6.5.1 Treatment Adherence Challenges

From the conversations with participants it seemed they attached considerable importance to treatment, as the only way to get individuals living with TB cured; emphasising that persons with TB needed to take their medicines as scheduled to be cured. The participants noted that the long duration for treatment was one of the major challenges for TB control. Successful completion of treatment, they reported, was an interplay of an individual's level of knowledge about the disease, their discipline to take the drugs as scheduled and an understanding of the consequences of non-adherence. One community leader, who is an HIV advocate, explained that processes existed for health educating persons about their medication, including the schedules for taking them. She

found those processes helpful in supporting people to complete their treatment. She, however, observed that there were still people who did not follow the treatment instructions in the community who required follow up at the community level:

“It depends on how well you know about the disease you have and the consequences of not taking your medication, which I find that in New Zealand we have ‘A+’ medical persons, we got ‘A’ medical team in New Zealand, that’s my observation. Normally they’ve got a process they’ll tell you how you should take your meds...there are people who actually don’t follow those things and which means in the community we need people to follow what we call people at risk. People at risk in the sense of not taking the drugs, the depressed people, actually mentally unstable people so they’re at risk of not taking their medicines so someone needs to follow up on that”. (CL01)

Participants believed treatment adherence among Africans was good. They underscored people’s educational level, their knowledge about the importance of treatment, their own life experiences with TB in their countries of origin, and the understanding that non-adherence to the treatment could lead to developing resistance to medication, as key contributors to the high treatment completion rate:

“Adherence is quite good with the African community and they also know that if you don’t adhere to the medical regime you may develop resistance to medication” (CL02)

“They do follow treatment so yeah it depends maybe on the individual may be because they’re also educated that’s why they know I need to get my treatment and need to follow it till the end” (CL04)

Although treatment adherence in general was good there were instances where persons on treatment did not follow to the satisfaction of their doctors, as one medical officer of health explained:

“If people are erratic and there’s a very difficult case I’m dealing with at the moment where the person has been really erratic in the last two weeks they’ve missed 8 out of 14 of their doses and they are on directly observed therapy but they’ve just gone missing for like six days in a row. So, that’s a very big concern for the specialist because they’re at risk of developing drug resistance TB so that’s a problem and we try to avoid those kinds of problem, it’s unusual but usually it has to do with social issues and substance issues and we know those things are involved in this” (HP02)

This participant, from the text above, admitted that non-adherence to treatment, although uncommon, does still occur, and was usually because of substance abuse and other social issues.

6.5.2 Healthcare Workers' Treatment of Africans

Community leaders expressed mixed feelings on how healthcare workers treated Africans during their visits to health facilities for care. Some were unhappy and felt the services delivered to them were unsatisfactory. Their perception was founded on the belief that some of their doctors were ignorant on some of the tropical diseases and would usually take a longer time in diagnosing them compared to their experiences back home:

“Some of the doctors in New Zealand are a bit ignorant when it comes to some of the tropical diseases for example malaria. I’ve discovered that the African doctors when the patient walks into the room before they take blood test and any scientific diagnosis by merely looking at a patient they can actually tell oh this is malaria straight away whereas in New Zealand they’ve to go through a tedious process of blood tests and it takes long and whatever and that can actually delay the proper treatment, which can be detrimental to the health of the patient” (CL02)

This community leader was convinced that most doctors in NZ might have a low index of suspicion for tropical diseases owing to the low number of cases seen in their entire practice life. This, he believed, could result in delays in further investigations. He was concerned about the seeming delays in confirmatory tests, which he believed could negatively impact people’s health. His perception seemed to be informed by clinician diagnosis and presumptive treatment, which often characterised treatment of such conditions as malaria in some African countries.

Again, for most African community members’ effective medical treatment meant that they should be given medicines once they visited their doctors, the leaders reported. This contrasted with what they experienced in NZ, where they sometimes did not get

prescriptions from their GPs when they visited:

“Most of us Africans are not really happy with the health system like when we visit our doctors because I remember that in Africa anytime you go and see your doctor your doctor has to prescribe a medicine for you but here myself I’ve been visiting a doctor that I’ve got a headache I’m not feeling well the doctor will just look at me and say go and drink a lot of water without any medication” (CL03)

This leader was dissatisfied with the NZ health system and believed so were other Africans. For him, one needed to take medicines to feel better when sick. Visits to the GP, he noted, were only when he felt unwell, and hence needed a prescription. He further emphasised that, even the type of medicine that were given to them by their doctors were sometimes not as effective as those that were prescribed when they visited an African doctor. Explaining why most of the Africans preferred African or Indian doctors:

“The type of medicine that the doctor will prescribe to an African will not be that really effective compared to when you visit an African doctor and say that you’re sick, the African doctor will know the right type of medicine to prescribe for you because what I know is that most of the doctors they just try some of the medicines to see if it works or not” (CL03)

Within the above extracts is the notion of mistrust between the community leaders and their healthcare professionals. This level of mistrust reflects the community leaders’ perception of what an effective delivery of healthcare services should entail.

Beyond the technical expertise and clinical service delivery, some community leaders expressed concerns over their members’ complaints about how some health professionals treated them. Some of them had the sense that their health professionals were prejudiced about who they were and treated them in ways that were less sensitive to their cultures:

“In general, I’ll say they’re treated well although from few of the community they feel like they’re not treated well in the sense that may be some of them find that when they go to see their GP there’s already a mind-set from them on may be putting them on some box so yeah but in general I’ll say the health system is quite fair to everyone” (CL04)

This concern was shared by the health professionals, who admitted to the occurrence of such issues but insisted that they rarely do occur and even when they do, they were not due to ‘deep-seated racism’ but more of ignorance on the part of some healthcare workers:

“It's still a shock because I worked in this area for over 20 years, it's still a shock to me when I encounter bad attitudes and manners around but I think often it's, you can tell me differently, more ignorance than deep-seated racism and you know that's why right training opportunities are so important” (HP01)

Whilst expressing her frustration over insensitive practices of some healthcare providers, this health professional was optimistic that the availability of cultural competence trainings could help in further reducing the occurrence of such poor attitudes.

Another reason for the seeming sense of discrimination felt by Africans and other migrants, according to one health professional, was the lack of official multicultural policies. She explained that the bicultural focus of policies prioritised Māori and Pacific peoples and quite rightly so, but it did not recognise the other high needs groups such as asylum seekers, refugees and other groups from high risk countries. Over the years there has been an increase in ethnic diversity but not an equivalent amount of funding or policies put in place that recognised who the population were now, she added. An increase in migrant communities along with an increase in families and communities with high and complex needs should require additional funding and specific policies in education, health or social development. She believed that the lack of policies to reflect the diversity and specific needs of the different cultural groups inhibits the ability of service providers to audit the cultural competence of their services:

“We still got a long way to go and we have a particular challenge I suppose in that the other receiving societies, so I'm talking about North America, Canada, Australia have official multiculturalism policies that mean that services are audited on their cultural competence. We don't have that because we are a multicultural nation sitting in under a bicultural framework and so we have some tensions around how all that works” (HP01)

However, one community leader disagreed with the notion that healthcare professionals discriminated against Africans. She opined that the NZ health system treated Africans well and that the discrimination, if any, that some community members felt was largely due to their own self-imposed discrimination and misunderstanding of the health care system, and their own misinterpretation of cultures or actions of their service providers. She explained that the seeming mistrust between some Africans and their healthcare providers could compromise the level of care they received because their providers would not fully understand their ‘case history’, which had implications for diagnosis and effective treatment:

“For years I didn’t trust them, I didn’t tell them what was wrong with me and with that trust I had with them, I couldn’t be cared for properly because with trust you get cared for, you get resources. So, if you’re hiding, you’re not telling people exactly what it is, you not going to get that and with the doctors is the same way, it works in two ways. So, I always saw doctors as if they were discriminating me and today as a person who’s evolved doctors are not trained to discriminate they are just doing their jobs but the discrimination we feel is a baggage we already been carrying about who we are” (CL01)

One way to minimise the mistrust between African communities and their healthcare professionals, this community leader mentioned, was to develop a properly structured system for the introduction of new members into their new societies. She explained that there was currently no such coordinated programme for new members, which left members to approach living in their new environments with the frame of reference being their past experiences shaping what they expected in their present lives. These two societies, however, were entirely different, she added.

6.5.3 The Immigration Policy and TB

Participants unanimously agreed that the immigration policy presented challenges to the early diagnosis and treatment of TB among migrants in NZ. All community leaders were aware of the immigration NZ policy on health screening before arrival:

“The policy is already stopping people if you’re not living in New Zealand you can’t come with TB at least you get treatment over there if you finish then you can have access to come here” (CL02)

They were also aware that those in-country needed to undergo medical screening whenever they applied for their residence permit. People who were ‘unfortunate to be diagnosed with TB’ while they were in-country were ‘often very fearful about what will happen to their immigration status’. Participants explained that such persons were often worried about what would happen if they decided to renew their visa and had to declare to immigration that they have been treated for TB:

“People who’re unfortunate to be diagnosed of TB while they’re here are often very fearful about what will happen to their immigration status particularly if they’re a visitor or on short term permit so they’re often very worried about what will happen if they’ve to declare to immigration that they’ve had treatment for TB” (HP04)

They further mentioned that persons who were declined their visa extension applications and had subsequently over-stayed or who had just decided to stay beyond their visas, were fearful of deportation and hence might not present themselves for any treatment:

“An over stayer also will feel scared of seeking for help because they know that if the doctor finds out that he or she’s an over stayer the doctor might call the immigration people to come and arrest him or her and deport him or her” (CL03)

“One, they’re overstaying so what’s gonna prevent them? They don’t want to expose themselves, I’m here I’m suffering I’m this so they feel they’ll be identified and may be they may not get treatment and they may be sent back to their own country because they’ve been overstaying so that could be something that’s gonna prevent them to go and access those services” (CL04)

These extracts reflect the sense of apprehension that illegal migrants living in NZ might have towards seeking treatment for any symptoms indicative of TB. Participants were concerned about the level of care illegal migrants received.

One of the main concerns for TB service providers was the lack of clarity and consistency in the implementation of the immigration policy rules as to who gets to stay or leave because of TB, which makes it difficult for health professionals to advise their clients appropriately:

“One of the difficult parts for me as a doctor is the way the immigration services work, it’s not very transparent or clear to me. So, patients will often ask us what is immigration going to say and I don’t actually know so we often have to work with sought of second hand information so there’s not much visibility to me as a doctor as to how immigration works. If a patient says to me doctor will I be thrown out of New Zealand for having TB I actually can’t really tell but I generally have to advise them that the best thing for you to do is to have your treatment. But sometimes it can be a barrier so sometimes people are reluctant to be diagnosed with TB or sometimes reluctant to take treatment” (HP04)

This health professional was concerned over what he perceived as his clients’ anxiety about their immigration status to the point they seemed less worried about their own health. He believed transparency and consistent application of the rules could help healthcare providers’ ability to appropriately counsel their clients and potentially contribute to reducing some clients’ reluctance to accepting treatment.

The application of the immigration rules was further mentioned and considered a barrier to effective treatment especially in cases of MDR TB:

“We’ve some multi drug resistance TB cases almost to the end of their treatment, and then they say you’ve got to leave which seems very foolish and short sighted. But others have stayed so we don’t understand it really.” (HP02)

Healthcare professionals cited examples of cases who abandoned treatment some months into their treatment requesting their doctors to allow them sometime to stay off TB treatment especially when they had some few months to submit their visa applications. Other times treatment was stopped because immigration had requested them to voluntarily leave or face deportation. Most of them, per participants’ recounts, left voluntarily in the belief that they might be allowed to return. The health professionals reported that there were a few that got deported but many of them left on their own accord

after receiving letters from the immigration department. The fear that, once deported, one would never be allowed back into the country forced many to leave voluntarily while on treatment. The majority of them were people on short term visas like study or work:

“If we look back at our records many patients with multi drug resistance TB have had their applications to stay in New Zealand declined. Sometimes while they’re still on treatment because the treatment is so expensive New Zealand immigration have either removed or not allowed people with MDR TB to actually stay in New Zealand even if they’re still on treatment. And while I can understand that because the treatment is very expensive I’ve often had concerns about the adequacy of the treatment they’ll get once they return to their country of origin and also whether there’ll be any interruption in treatment it does worry us as clinicians” (HP04)

This specialist was concerned about the quality of care that persons on treatment for MDR TB would receive in their own countries after being deported or leaving voluntarily. The interruption in treatment, he stated, could worsen treatment outcomes for such persons and could potentially remain a public health threat if such individuals returned.

Like in other countries who undertake to fully treat the person once they have started, NZ must also undertake to fully treat all persons with TB. This, the healthcare professionals believed, was the way to go. They wanted to see that at least people have their visas extended for the period of the treatment, whether for six, nine months, a year or even for up to two years for MDR TB. That, to them, will be the humane and ethical thing to do:

“In other countries, they undertake to fully treat the person once they’ve started and I really think that would be the way to go, I mean drug sensitive TB isn’t expensive to treat once the person is finished their hospital bit if they need to be in the hospital that’s obviously quite expensive but once you’ve done that is not very expensive. Multi drug resistance TB is expensive but what will be much more expensive is getting someone with multi drug resistance TB out not properly treated and then if they come back with extensive drug resistance TB that will be a disaster, so it’s very short sighted” (HP02)

6.5.4 Racism and Discrimination

Racism was identified as one of the structural factors affecting the health and wellbeing of Africans, and had implications for TB prevention and care activities.

Participants considered societal racism in NZ to be relatively low. However, they believed that institutional racism and discrimination such as that which occur at schools, health facilities and in employment were high:

“In New Zealand, you know societal racism is very minimum but in terms of employment that’s where you get it and in institutions” (CL02)

There was a general feeling among community leaders that their communities were neglected. For them, their relatively small number was one of the reasons accounting for the seeming neglect. Although several African community groups existed in NZ, the leaders believed they had not received the needed recognition from authorities and were not actively engaged at the highest level of decision making even in matters that directly impacted their communities:

“I always emphasise that, because of how small the number we are, that’s why we are really quiet because we are suffering for just being a smaller group...we need to be recognised, we need to be acknowledged that we’re actually clever people and I don’t see that, nobody acknowledges that”. (CL01)

The leader was convinced that having a small population size was not enough justification to deny their uniqueness and existence as a group. She expressed her frustration at the denial of Africans from participating in matters that affected them. She reported that a previous study involving community leaders and members in 2013 had recommended to the Ministry of Health to constitute an advisory team responsible for making health decisions for the African community. To her disappointment, the ministry agreed and set up a reference team for Africans without any African in its membership:

“We need to actually have some kind of African health department where Africans look after themselves. Something that was actually recommended by Massey University when they did the HIV for Africans study 2013. I was part of that and the recommendation that came out of that was Africans need to look after themselves and the Ministry of Health after they got the recommendation formed what they called a reference group but surprisingly the reference group didn’t include Africans. So still we do that we get all this information the Africans are not included in a reference group for Africans.” (CL01)

It was frequently mentioned in the interviews that some Africans felt discrimination in the process of seeking employment. One community leader recounted instances where Africans had faced discrimination in schools and in their pursuit of employment due to their colour and accent:

“I know an African guy, a Sudanese who was born in the US, speaks really good English. So, he applied for a job, had all the qualifications, they did the initial interview over the phone and they were so happy because they thought the person was a white American. So, they called for face to face interview the guy went there and the person interviewing him said is that you that I spoke to over the phone, because when he saw that he was black he was surprised. So, the one hour interview only lasted for 15 minutes and within few hours that the guy left the office he received an email that they’re sorry he wasn’t successful, all this shows that a lot of racism exist here in NZ”. (CL03)

Within this extract the leader was emphatic and concerned about the perceived discrimination against Africans living in NZ on the basis of their skin colour and accent. The leader emphasised that the challenges of employment for Africans was mainly due to employers’ prejudice about the competencies of black people and not necessarily their accent or lack of qualification. He noted that such acts of discrimination hindered the progress of well qualified Africans in their field of work and ultimately impacted on their health.

Community leaders’ perception of racism was corroborated by some health professionals who believed that the wider community and the institutions including healthcare providers were not as tolerant as required:

“In the wider community, I think that many of them might have observed their neighbours, children school and the institutions they interact with in the wider community wouldn’t necessarily be tolerant and could be very racist and destructive” (HP03)

Such discrimination, they believed, could impact Africans accessibility to healthcare services leading to delays in reporting. They explained that, in the case of TB, many

Africans might delay until symptoms were severe in the hope that the symptoms would disappear, and to avoid the unpleasant encounters with the healthcare institution. This could be due to their own experiences of discrimination at such facilities or the perception of discrimination resulting from their family members or acquaintances recounts of experiences in such facilities.

It was evident from the discussions that healthcare providers sometimes refused to engage migrant communities:

“They don't respond to the invitations to meet and they don't respond to written feedback and request for feedback so they just ignore them”. (HP01)

This health professional believed that migrant communities' inability to respond to invitations to meet or to provide requested feedback were not sufficient grounds to ignore them. She asserted that this population group had complex health needs and should be encouraged to actively participate in the delivery of healthcare.

6.5.5 Barriers to TB Services

Throughout the interviews participants identified and discussed what they perceived as barriers to the utilisation of healthcare services in general and those specific to TB among the African community. Community leaders mentioned the lack of community engagement activities as a huge challenge for them:

“We rarely hear about it”. (CL01)

“I don't think people know or people share that or people discuss about it because as I've said they're not aware that TB is here or it could be just few people who know because they've been diagnosed with TB so they may know. And also what they know is may be when someone will like to come here and immigration asks them to do the lab test and medical exam to make sure they don't have TB and once they are identified with TB they can't get to come here so that's the only prevention that they're aware of and for the refugees when they have TB or HIV they can bring them here so that's the prevention they know and that's known by the community, but anything else is unknown because no one talk about it or say

anything about it at least in the African community there's nothing, nothing at all". (CL04)

These leaders explained that the lack of community sensitization activities in their communities had contributed to the perception that there were no TB in NZ. The health professionals agreed with the assertion of the community leaders. They explained that they were constrained by the lack of resources to do such community engagement activities, as they had done in the past. They further mentioned that TB was generally not as 'attractive' as other diseases and not on the list of priority diseases of decision makers:

"We haven't done one for the last few years because of resource constraints"
(HP01)

"So, there're challenges and these challenges are the same as all countries like ours because TB isn't top of the list is not even on the list sometimes" (HP02)

Community leaders were concerned about the low representation of Africans within the healthcare system. They believed getting enough Africans in key institutions would help build the confidence of their members in seeking services:

"I think the barrier I'm hearing all the time in the community is we don't have our own people I really hear that quite a lot...We need more people in this political, health services, we need more Africans channelled into HIV, social workers, psychologists, nurses, those areas are very important" (CL01)

Participants further identified the lack of knowledge about available services and the disconnect between what families perceived the health services to offer and what it actually offered as an important barrier to service utilisation. According to them, there were several support systems in NZ, but they were unfortunately wrapped up in bureaucratic systems that were difficult to navigate and hence inaccessible to most migrants:

“In terms of the issue of health, there’re challenges because people don’t know. We got good support systems in New Zealand but they’re very difficult to navigate because of the bureaucratic system. People don’t know where to access these services so accessibility is an issue” (HP03)

“A lot of the barriers too are that divide between what the family understands the health sector to provide and what is actually available” (HP01)

According to participants, navigating the health system was a ‘nightmare’ even for the NZ born. Stressing that one needed to push to demand what they were entitled to:

“Even for New Zealand born people it’s a nightmare navigating your way through the benefits and the different service providers. You have to really push to actually get out of the system what you are entitled to” (HP01)

They believed that most migrants, including Africans, did not have the skills and courage to ‘push’ out of the system what were their rightful entitlements.

Another barrier that consistently came up across all the interviews was money. Participants believed it was one of the key reasons why people did not seek health services:

“The money as well, the financial side because going to see the GP costs money. Some GPs charge \$15, some of them charge \$20 and others charge \$25 so somebody on low income just to go and see the GP to pay \$20 you know is a challenge for them so money is also a barrier because the person will be receiving \$170 a week paying the rent of \$120 so its left with about only \$50 so why should the person go and spend \$20 for the consultation fees plus you have to pay for the prescription as well” (CL03)

“Cost is a barrier for many families here” (SO01)

“Income, especially if you’re on treatment that’s not funded and you need to go over the counter and pay so that’s another barrier and also even going to the GP because of the income sometimes it’s hard for people to go not only because of the language but thinking of how you gonna be paying for your GP so that has been another barrier especially income is quite a huge barrier” (CL04)

The extracts above seem to suggest that money is a huge barrier to healthcare access in NZ among Africans. Participants mentioned that, although TB treatment was free,

persons with symptoms suggestive of TB needed to pay for their initial consultation visits to their GPs. The cost of these initial consultation could be too expensive and prohibitive for some families preventing them from reporting for early diagnosis and treatment.

6.6 Discussion

There were key findings from the analysis of the interviews that related to the aim of the second phase of the study “to understand the factors that contribute to the relatively high rate of TB among Africans living in NZ”.

6.6.1 Settlement/ Integration Difficulties

The findings from this study suggest that African migrants experience difficult challenges during the process of integration into their new environment. This may influence the activation of previously acquired TB or the acquisition of TB from their new environment. This finding is consistent with that of Henrickson and his colleagues who, in their study on the knowledge, attitudes, behaviours and beliefs about HIV among black Africans living in NZ, reported that participants experienced difficulties in adapting to the host culture (Henrickson, Dickson, Mhlana, & Ludlam, 2013). Moving to a new country requires adoption of new behaviours, values and language (Berry, 1997). This process of acculturation, adapting to the new culture while maintaining one’s own, which might not necessarily be accepted by the dominant cultures, might lead to stress and risky health behaviours (Berry, 1997; Winbush & Selby, 2015). Lawrence observed in her study of Somali refugees, that most of her participants still grieved over their separation from families/ friends and the loss of familiarity with their natural environment (Lawrence, 2007). Grieving over losses, particularly within the first few years of arrival,

has been demonstrated to be compounded by the sense of isolation from the wider society of the host country and the feeling of disappointment for some who had hoped for a better life upon arrival but found living in their new home to be more difficult than anticipated (Lawrence, 2007; Winbush & Selby, 2015). In the current study, participants identified difficulties with getting employment, issues of language, poor living conditions and lack of awareness of available services as important challenges.

While securing the right type of employment has been linked to improved psychological and physical wellbeing, underemployment or unemployment is an important determinant of ill health (CSDH, 2008; Marmot, 2005). Among refugees, employment has been shown to be an important determinant of mental wellbeing as it mitigates worry and depression (Stephenson, 1995). In this study employment was identified as a significant source of stress for new members of the African communities, similar to previous findings among skilled African women immigrants living in NZ (Adelowo, 2012) and among Ethiopian and Somali refugees in Toronto (Danso, 2002). Some common reasons for denial of job opportunities, as identified in the current study, included: English language/ accent; unrecognised qualifications; no NZ experience; and institutional racism. The enumerated reasons or mechanisms interact at different levels, regardless of our knowledge of them, to limit the integration of Africans into their new environment and could be used as grounds to discriminate against them. It is reasonable to suggest that the persistent stress from unemployment or underemployment, within the context of the high hopes that most Africans might have travelled to find jobs and improve their living conditions, could significantly impact their body defence mechanisms triggering previously acquired, but dormant, infections like TB to activate. For instance, it has been reported that migrant health professionals from non-English speaking countries expressed feeling disappointed, hopeless, depressed, undervalued and frustrated

due to the difficult barriers they encountered in their attempts to practice as registered professionals in NZ (Mpofu & Hocking, 2013).

Linked to employment is the issue of status loss and limited opportunities for mobility in one's status (Berry, 1997). Most people, due to non-recognition of their education, working experience and underemployment, are likely to have their pre-immigration status devalued in their new setting (Danso, 2002). It could be the case, as indicated earlier, that such unexpected degrading of one's status may lead people to health risks such as stress, depression, malnutrition and general feel of unwell, which might increase their vulnerability to other diseases including TB. The lack of coordinated and systematic support for the integration of Africans into their new communities could be an important contributor to their vulnerabilities to TB, especially within the first few years of arrival. While this study presented new insights on integration and TB vulnerability, further study on how new Africans adapt to the new society is warranted.

6.6.2 What Individual Factors?

The findings suggest that African communities in NZ could be aware of TB but might not have adequate knowledge on the biomedical explanation of TB, which has the potential to limit individuals' ability to identify symptoms early on, leading to delays in seeking help. While some participants were confident in explaining the causes of TB, others were not and were ambiguous in their answers, which reflects generally poor knowledge on TB. This finding agrees with other findings elsewhere (Gerrish et al., 2012; Nnoaham et al., 2006; Sagbakken et al., 2010).

Participants commonly embraced other perspectives to explain the causes of TB. Most of these perspectives related to the socio-economic circumstances of individuals including poor housing, poor nutrition, and overcrowding. A common misconception

among African community leaders was that TB was not present in their new setting. They believed that TB was a disease of the poor, common in poor countries and that their new environment was safe from some infectious diseases like TB - “*there’re no such diseases here*”- hence could not be victims of TB. Such low risk perception is consistent with existing literature (Sagbakken et al., 2010). While enough evidence about the link between TB and poverty exists, such strong perceptions, as identified in this current study, might lead African migrants to perceive themselves as unlikely to develop TB. Again, using such frames of reference, symptoms of TB are likely to be misinterpreted and unreported (Naidoo et al., 2016). A possible explanation for the low perceived susceptibility might be that most participants were unfamiliar with the concept of latent TB, which could progress to TB disease at a later stage. A high sense of vulnerability or risk about a disease could influence a positive response to the disease (Janz & Becker, 1984). It could also be the case that most African migrants were used to receiving health messages on TB in the media or from health facilities in their countries of origin. However, the sudden switch from media messages on infectious diseases to that of life style related diseases, might have contributed to the current belief that TB is non-existent in NZ as reported. Further studies on priority health issues among this group is warranted to help understand how their new society might contribute to shaping current beliefs.

6.6.3 What Social Factors?

In this study, like other previous findings, there was a high social stigma attached to TB. This high stigma was perceived as a barrier to TB services, linked to social isolation, and a barrier to public health action such as contact tracing (Gerrish et al., 2012; Nnoaham et al., 2006). The findings suggest that the key drivers of stigma within the African community were the fear of TB as a deadly contagious disease, the threat of isolation/discrimination or loss of social ties, the perception that HIV was the underlying

cause of TB and the notion that TB is a disease for the ‘other’ (migrants) with its associated negative stereotypes (Macintyre et al., 2017).

Participants believed TB was hidden, less spoken of and rarely disclosed out of fear of being stigmatised and isolated by community members. In her doctoral thesis, Lawrence showed that considerable efforts were made to hide TB within the Somalian community, beginning early on when participants were admitted at the hospital, where other family and friends were prevented from visiting (Lawrence, 2007). Interestingly, participants believed that TB might be concealed because of the negative labelling of African migrants as a source of diseases such as TB and HIV, and the associated shame or stereotypes that come with such labels towards their communities (Craig et al., 2017). Linked to this is the idea of power and domination wherein the concept of stigma leads to certain groups feeling devalued while others are valued in ways that are discriminatory (Link & Phelan, 2001; Parker, 2012). Concealing TB within the community might therefore be an active response from the community to reject such labels from dominant cultures (Link & Phelan, 2001). The implication, however, could be that stigmatised groups might be socially excluded by the dominant forces, and may not be willing to access available services for fear of being labelled and rejected (Craig et al., 2017). These could present challenges particularly around contact tracing as admitted by the health professionals interviewed in this study.

Another important finding from this study was a strong perception among community leaders about the link between TB and HIV. They believed that TB, within the African communities, was regarded as ‘similar’ in severity to HIV. It was commonly perceived as a precursor to HIV, and that any individual diagnosed with TB could have an underlying disease, most likely HIV. TB within the African community may attract a double stigmatisation from both HIV and TB (Daftary, 2012). Previous studies among Africans have demonstrated that HIV is highly stigmatised within the African community

in NZ and most persons living with HIV were less likely to disclose their status (Henrickson et al., 2013). It is reasonable to suggest that the high sense of fear and shame associated with the HIV labelling could be due to the perception that HIV is a death sentence and an outcome or ‘punishment’ for individuals engaging in unacceptable behaviours (Daftary, 2012). This perception was well captured by a participant’s quote from a study about the experiences of HIV positive Black Africans in NZ (Fouché, Henrickson, & Poindexter, 2011):

“If they know that there is someone with HIV, it becomes like a gossip. So that’s why you find people, when they find out that they are HIV they want to keep it a secret, they don’t want to share it with anyone” (Participant quote p.16)

These negative stereotypes about HIV may be transferred to TB compounding the fear and shame, and might contribute to the need to hide one’s diagnosis or from getting diagnosed.

6.6.4 The Poverty Complex

The findings from the interviews suggest that most African migrants’ socio-economic status is low and they are faced with difficult economic challenges, which contributes to the relatively high rates of TB among them. The association between TB and poverty has long been studied and remains one of the common perspective in explaining the causes of TB, together with biological factors such as exposure to the bacilli (Barr et al., 2001; Bhatti et al., 1995; Cundall & Pearson, 1988; Goldman et al., 1994; Mangtani et al., 1995). While evidence abounds on poverty as an important determinant of TB, the complexities around understanding the role of poverty and the seemingly enormous task of eradicating poverty has contributed to the overemphasis on the biomedical model for eradicating TB (Lönnroth et al., 2009). Admittedly, the

biomedical approach presents a comparatively easy way to quantify outcomes but is limited in addressing the underlying factors.

In this study participants seemed convinced that most members of their communities lived under challenging circumstances. The increasing cost of housing, as stated earlier, has contributed to overcrowding and individuals resorting to living in cold and damp houses, which increases their vulnerability to TB (Baker, Das, Venugopal, & Howden-Chapman, 2008). In addition, challenges with securing ‘well-paying jobs’ due to issues of language, information, the needed skills to navigate systems and non-recognition of qualifications from home countries have contributed to the perceived poor living standards of this group: the cascading effect of which may have been increased vulnerability to acquisition or activation of previously acquired TB.

While economic conditions may increase vulnerability to TB, being diagnosed with TB could further worsen an already poor living circumstance (Barter et al., 2012). The study found that, although some support systems were available to minimise the financial burden on individuals/families, most African leaders interviewed in this study were not aware of such. Once diagnosed, individuals received support from the organization based on the assessment and recommendation of their public health nurses. However, the lack of information about such support within the African community could contribute to delays/ unwillingness of persons with symptoms suggestive of TB to report for treatment. As participants noted in their stories, TB could be costly to individuals and their families, both in NZ and back home. Hence, any support aimed at making life more bearable could positively influence decisions to seeking help early on when symptoms are apparent.

6.6.5 What Structural Factors?

The findings from the study suggest that African migrants might have issues of mistrust around healthcare providers' competence relative to appropriate treatment and medication. The notion that some African migrants received sub-standard services was partly blamed on the lack of official government health policies with a multicultural focus (Berry & Sam, 2013). While the migrant population in NZ has continued to grow over the last decades, there has not been commensurate policies that acknowledge the increasing diversity; specific policies targeting vulnerable groups are non-existent. The NZ society tolerates the presence of diverse cultures, however, there seems to be a lack of emphasis on deliberate equitable programmes to promote inclusion and active participation of the 'other' because of the bicultural focus, and rightly so, of government policies (Berry & Sam, 2013). Hence, auditing of these services for their cultural appropriateness might be a challenge as guidelines on what services should entail are largely unavailable.

Furthermore, the immigration NZ policy was identified as a significant barrier to TB elimination efforts. This is an important finding as no previous study among Africans has sought to understand this. In a report by Henrickson et al. (2013), they identified the existing immigration laws as a 'source of distress' for their participants. In this study, it was identified that the policy could contribute to non-reporting of TB symptoms as persons might be fearful of deportation. While community leaders were worried about the trend of deporting persons already under TB treatment, healthcare professionals were distressed by the lack of clarity in the implementation of the policy by immigration NZ. They reported instances where persons on treatment were asked to voluntarily leave the country or be deported. The notion that reporting for TB could lead to one being deported may force persons who were already over staying their visas or needing to apply for

residence visa to hide their symptoms or avoid the mandatory screening process respectively. While individual knowledge about symptoms of TB could positively influence health decisions, concerns about one's immigration status has the potential to prevent actual behaviour. Potter, for example, has argued that the recent introduction of a formalised process to allow the Health and Social Care Information Centre (NHS Digital) to transfer demographic data to the UK Home Office Immigration Enforcement Team was counterproductive and a major setback to TB elimination efforts, as most migrants, especially illegal migrants, would be deterred from seeking healthcare services for fear of deportation (Potter, 2017). The immigration policy, which is a distal determinant (Lönnroth et al., 2009) may be playing a more significant role in TB control than anticipated and would require further study to assess its impact on TB control efforts in NZ.

The findings seem to suggest that African migrants face racism and discrimination at schools, health facilities and in the search for employment. Such experiences with institutions in the wider society, which may not necessarily be tolerant of Africans, could influence their decision to interact with service providers when they need help. In addition to the challenges of institutional racism, community leaders felt strongly that their communities were neglected, largely because of their small population size. While previous studies have recommended active involvement of Africans in decisions about matters of health (Henrickson et al., 2013), the same remains to be implemented. This sense of neglect, to the extent that the Africans feel marginalised in decision making about matters affecting them, could deepen the 'us' and 'them' feeling (Link & Phelan, 2001). This has the potential to further widen the inequality gap as institutions mandated to address their issues might be considered not friendly enough.

Interestingly, but not surprising, TB was identified as less attractive and not on the list of priority diseases in NZ. The low number of cases notified yearly might have contributed to it being less important in attracting resources. Healthcare professionals were concerned about their inability to engage vulnerable communities because of resource constraints.

6.7 Summary

This chapter has presented the main findings from the phase II study. Five main clusters were identified from the interviews with participants as the main determinants of TB among Africans – settlement/integration, individual, social, economic and structural factors. The findings suggest that African migrants face difficult challenges throughout the settlement/integration process, which may influence their vulnerability to TB disease. It also suggests that many Africans may perceive themselves as least vulnerable to TB and hence would likely delay in seeking treatment. The chapter revealed that TB may be stigmatised even in a low incidence country and might attract a double stigma from its perceived link to HIV. The chapter presented the challenges with finding jobs and showed how the low incomes of many Africans may influence dietary habits, housing and general living conditions leading to compromised immune defence mechanisms. Furthermore, the chapter explained how structural factors such as service organisation, immigration policy and low priority for TB may influence the decision of African migrants in seeking services. The next chapter will integrate the key findings from both phases of the study and will simultaneously discuss these findings to demonstrate how each study complements the other in explaining the observed pattern of TB among Africans.

Chapter Seven – Understanding the African TB determinants:

‘Mixing up’ phase I and II findings

7.0 Introduction

The preceding chapters presented the findings from the two phases of the study. Key findings from each phase were subsequently discussed. In this chapter, the key findings from the two studies are integrated and discussed simultaneously. This is relevant as it provides a depth of understanding of the results from each study (phases I & II); with the findings of each phase complementing the other. In addition, the discussions in this chapter, together with the preceding one, set the scene for the concluding chapter, which includes the recommendations for public health action.

7.1 The Elimination Challenge

This study is the first to provide a descriptive epidemiological analysis and to elucidate the determinants of TB among persons born in sub-Saharan Africa living in NZ. Although the national TB rate declined, the rate of decline was slow, being less than 1 (0.14) per 100,000 population annually over the period under study. This trend was lower than the required estimated annual decline rate (11%) to achieve the TB elimination targets by 2050, suggesting that NZ might be missing out on eliminating TB if prevention and care efforts are not intensified (Lönnroth et al., 2015).

7.2 African Rates Declining

Like other comparable countries, foreign-born persons continue to be disproportionately affected by TB (Pareek, Greenaway, Noori, Munoz, & Zenner, 2016). While the foreign-born population constituted about a quarter (25.2%; 1,001,787 people)

of the entire NZ population, they contributed the highest proportion (77.5%) of TB cases. Africans had the highest rate of TB and the largest decline over the period albeit statistically insignificantly. Three likely reasons for the declining TB incidence among Africans are offered based on the discussion with participants and from the literature.

One of the likely reasons for the declining TB rates among Africans may be the sharp reduction in the number of quota refugees from Africa. The available evidence suggests that refugees are at an increased risk of developing TB and have been a significant source of TB in the past, between 1992 to 2004, among Africans living in NZ (Das et al., 2006; Howie et al., 2005; Lawrence, 2007). An analysis of available two ten-year immigration data on quota refugees revealed that, between 2006 and 2009, there were 549 quota refugees with an African nationality (19.2% of all quota refugees), declining by more than half to a total of 201 (5.8% of all quota refugees) between 2010 and 2014 (Immigration New Zealand, 2017). These figures, on the number of African quota refugees between 2006 to 2014, pales out in comparison to that between 1992 (when the first African quota refugees from Somalia resettled in NZ) to 2001; Africans constituted 43.2% (2,981) of all quota refugees [1,141 quota refugees of African nationality between 1992-96 (34.8%) and 1,840 between 1997-2001 (50.9% of all quota refugees)]. Whereas the evidence might be inconclusive, it may be reasonable to suggest that the reduction in the African quota refugee numbers may have contributed to the decline in African TB rates over the period. The changing African migrant composition to NZ may influence the incidence of TB in the future and warrants further longitudinal study to understand the risk patterns among the different migrant groups.

Another possible reason for the observed decline in the African TB rates over the period is the continuous decline in TB rates on the Africa region (see chapter two). As noted earlier, the risk of developing TB among migrants in low incidence countries reflects patterns in source countries (Baker, Winston, Liu, France, & Cain, 2016; Das,

Baker, Venugopal, et al., 2006; WHO, 2015a). Hence, any decline in the countries of origin is likely to impact TB incidence in the receiving country (Baker et al., 2016). With TB rates declining on the Africa region, it is expected that the prevalence of latent TB infections would decline proportionately as sources of infectious TB within the community is reduced. Thus, new African migrants are less likely to be exposed to TB infections in their countries of origin before travel and less at risk of developing TB in their new country.

Pre-immigration screening of African migrants may have also contributed to the declining TB rates. Pre-immigration screening was introduced in 2005 and requires individuals intending to stay in NZ for more than 6-12 months to have a chest X-ray before arrival. The aim is to identify persons with active pulmonary TB, who would receive treatment before travel (Ministry of Health, 2010). Whereas evidence of randomised trials evaluating the effectiveness of immigration screening do not exist, the available evidence seems to suggest that pre-immigration screening contribute to the declining TB incidence in receiving countries (Aldridge et al., 2016; Alvarez et al., 2011; Baker et al., 2016; Pareek et al., 2016). Screening is more likely to identify persons with active or sub-clinical disease who will receive treatment for TB before emigrating, minimising the risk of imported active disease. The likely reasons offered for the declining TB incidence among Africans is supported by Fojo and colleagues, who observed that the decline in TB rates in New York was best explained by a reduction in imported sub-clinical TB disease or the decline in progression from LTBI to TB disease among foreign born persons (Fojo et al., 2017).

7.2.1 The Age Factor

In common with other findings elsewhere, the Africans with TB were relatively younger when compared to other foreign and NZ born (Abraham et al., 2013). This finding reflects the age structure of Africans living in NZ and the general perception that most people migrate at a relatively young age to make the most of their migration investments. The recent census suggests that the African population is relatively young, median age of 24.3 years compared to the entire NZ population, median age 38.0 years (Statistics New Zealand, 2013). Among NZ and other foreign born, TB was commonly reported among retired persons. Conversely, the retired group were the least source of TB among Africans. Persons aged 65 years and over constitute the least age group (1.9%) among Africans and pales out in comparison to those 65 and above from the overall NZ population (14.3%) (Statistics New Zealand, 2013a). Although fewer Africans aged 65 and above reported TB, they present an important future challenge for TB prevention and care efforts. As the African population continues to grow in number over time, it is expected that the 65 years and above age group will rise proportionally and with that an increased risk of TB disease. Further research on TB prevention strategies among the migrant aged group is warranted, given that they pose an increased risk of developing TB disease from the likelihood of reactivation of latent TB due to the natural processes of ageing and its associated weakening of the body's immune system.

7.3 The Socio-economic Challenges: “The First Few Years are the Most Difficult”

Over one in five (23.9%) of all African TB cases were notified within the first year of arrival, common with other findings elsewhere (Kempainen et al., 2001; Varkey et al., 2007). It was identified from the interviews that stress from migration and integration into the new environment may contribute to the high risk of TB notification

within the first-year post arrival. This study found that accessibility to skilled jobs reflecting qualification/ previous experience, good accommodation, health services and other social support were largely challenging, especially within the first year. The most important concern for people in the transition phase was to survive, pushing most into less skilled and underpaid jobs. Such unanticipated difficult living conditions could impact individual's immunity leading to high risk of reactivation of previously acquired infections or acquisition of new ones.

The findings from the quantitative analysis further suggest that TB affects people living in the most deprived small areas in NZ irrespective of their country of birth. Notably, persons living in the most deprived 20% of the small areas in NZ reported the highest proportion of TB cases among all the three groups compared. Among Africans the findings further showed that one in five (20%) of all persons with TB were unemployed. This was further explained by the findings from the interviews, in which participants emphasised that most Africans, especially the new entrants, lived under difficult circumstances and faced economic challenges including securing employment. The strong association between poverty and TB has long been established albeit debated in literature about the complexities associated with understanding poverty at an individual level (Barr et al., 2001; Bhatti et al., 1995; Cundall & Pearson, 1988; Goldman et al., 1994; Mangtani et al., 1995). As in this study, the NZDep2013, an index of deprivation used to measure the level of deprivation in meshblocks in NZ, was used rather than individual deprivation levels. However, as a proxy indicator for the level of socioeconomic deprivation it helps in understanding the link between deprivation and health (Atkinson et al., 2014)

Added to this, the 2013 census data points to an African ethnic group that is somewhat deprived socioeconomically. Approximately 51.6% of persons who identified with the African ethnicity earned \$20,000 or less annually, 30.4% were on some form of

income support (including unemployment benefit, sickness benefit, domestic purpose benefit and other government benefits), 81.5% did not own their homes, about 12% living in rental accommodations paid less than \$100 a week, which might be an indication of the quality of homes, and 15% were unemployed (Statistics New Zealand, 2013a). Previous findings suggest that poor housing and overcrowding are important contributors to TB in NZ (Baker et al., 2008). These findings are significant for TB prevention and treatment efforts. Admittedly, improving socioeconomic circumstances of vulnerable groups is beyond the health system. However, the gains from such interventions have the potential to significantly impact an individual's health including eliminating TB (Lönnroth et al., 2015). Complex interventions aimed at addressing the underlying socioeconomic challenges are key to achieving the TB elimination targets, as has been shown elsewhere in the past (Frieden et al., 1995; Paolo & Nosanchuk, 2004; Wallace, 2001).

7.4 The Structural Factors: Treatment Issues

The quantitative analysis showed that the treatment success rate was relatively high but did not increase statistically significantly over the period. Although efforts were made to sustain and increase the treatment completion, some barriers to treatment were identified through the analysis of interview data. The findings from this study seemed to suggest that the immigration policy contributed to the number of people interrupting their treatment. This assertion was supported by the analysis of the quantitative data, which showed that 64 cases (4.5% of all cases) left for overseas, 28 cases transferred out for overseas medical care and five were lost to follow up. The fear of deportation and refusal of a visa might have influenced the decisions of persons on treatment to voluntarily leave or to interrupt treatment. In some cases, as reported by the health professionals, the

immigration policy contributed to late reporting and decisions by people to give up treatment completely even before they were cured. This finding confirms a recent systematic review of risk factors for non-adherence to TB treatment in immigrant populations, which concluded that immigration status was consistently associated with treatment adherence (Lin & Melendez-Torres, 2016).

Treatment delay for infectious TB is associated with transmission to other susceptible individuals, with longer delays more likely to result in infection (Golub et al., 2006). Treatment delay has also been shown to be strongly associated with severe clinical presentation elsewhere (the greater the delay the more unwell infected persons become) (Virenfeldt et al., 2014). Interestingly, while the Africans with TB had the highest treatment success rate, they had the longest delay of the three groups in seeking treatment. Approximately 56.5% of Africans received treatment within the first three months of the onset of symptoms. The high treatment completion rate among Africans confirms previous findings elsewhere, which found that most Africans believed TB treatment was effective and were more likely to complete their treatment (Abraham et al., 2013; Gerrish et al., 2013). The findings from the interviews suggest that the delays among Africans might be due to the interplay of personal (a low perceived susceptibility to TB disease in NZ), social (issues of stigma) and health system factors (lack of awareness about available services, cost, mistrust of healthcare providers, immigration issues, language) common to that of previous studies in NZ (Anderson, 2008; Calder et al., 2000; van der Oest et al., 2005).

At the individual level, the misconception that TB does not exist in NZ could have contributed to the delays. The study identified that the seemingly low perceived susceptibility to TB among the Africans could be due to the lack of TB awareness-creation campaigns within the communities. As stated by one leader “we rarely hear about it”. While health professionals had previously engaged communities in TB sensitization

activities, the study found that this was not the case during the past five years. They were constrained by resources to undertake such programmes. This affirms the common notion that TB is less attractive and may not even be on the list of priority diseases in many of the low incidence countries (Lönnroth et al., 2015).

Additionally, most Africans, especially recent arrivals, could be unaware of available services and entitlements such as free TB treatment (Dhavan et al., 2017). For the few that were aware of social services, additional constraints such as the complexity of the healthcare system and language proficiency were identified in the current study as important barriers to healthcare access. Money was another important barrier, as the initial cost for consultation visits to GPs, especially for individuals already constrained financially, could be prohibitive. There is increasing evidence of an unmet need for primary care services in NZ due to the relatively high cost of services (Keene et al., 2016). At the social level, factors such as high stigma associated with TB and the double stigma of HIV and TB could contribute to the delays in seeking treatment.

Another important finding that affirms Africans believe in TB treatment was the proportion on treatment who received directly observed therapy (DOT) in the intensive phase of treatment. The results showed that Africans were the least group to receive DOT compared to NZ and other foreign-born persons. The guidelines for TB control in NZ (2010) recommends three levels of supervision: DOT, which requires the person with TB to swallow the medication in the presence of the public health nurse (PHN) and must be done daily or thrice weekly; in Self Medication, the person with TB takes the medication daily without supervision (a parent administers in the case of a child) and the PHN visits within 28 days and; close supervision requires persons with TB to take their medication daily with the PHN visiting at least weekly. DOT is recommended for persons: with highly infectious disease; who fail to comply with clinic requests; poor adherence; and unable or unwilling to self-medicate among others (Ministry of Health, 2010). The

proportion receiving DOT is an indication of the disease infectiousness and the risk of poor adherence, which could lead to poor treatment outcomes and MDR TB. It is reasonable to suggest that the low proportion of Africans on DOT might indicate that most were likely to be less at risk of poor treatment adherence and willing to self-medicate. This, advances and strengthens previous findings about Africans' belief in the effectiveness of TB treatment.

7.5 Summary

The chapter has discussed the main findings from the two studies and demonstrated how the two phases complemented each other. It indicated that although there has been a decline over the period, the rate of decline was insufficient to attain the elimination status. It demonstrated that the high proportion of TB notifications within the first year of arrival may be due to the difficult settlement/ integration process for new Africans. The chapter further highlighted how the economic conditions of some Africans may influence their vulnerability to developing active TB disease. Finally, it discussed the common structural barriers to the utilisation of TB and other healthcare services. It noted that, Africans had high treatment success rates but delayed in seeking help probably due to misconceptions about TB, initial consultation cost, awareness about available services and fear of deportation among others. The proceeding chapter will draw on the current to demonstrate the implications of the study and offer some recommendations for policy, practice and research.

Chapter Eight – Conclusion: Eliminating TB, Improving Health Outcomes

8.0 Introduction

The preceding chapters provided an in-depth discussion of the determinants of TB among African migrants. It established the context of TB within the sub-Saharan Africa region (Chapter two) and demonstrated how African migrants may be at risk of latent TB infection. Current literature on the factors contributing to TB among Africans living in western countries was synthesised (Chapter three). The methods employed in this study were further explored and justified (Chapter four). The main findings from both phases of the study, the epidemiological analysis (Chapter five) and qualitative study (Chapter six), were presented and concurrently discussed (Chapter Seven). In this final chapter I consider the theoretical implications of the findings from this thesis and re-apply the conceptual framework (Section 4.1) to explore these.

8.1 The “African Hut Model”

In the introductory chapters, I situated this study in an ecological framework underpinned by a critical realist philosophy. I have argued that the incidence of TB is likely the result of a complex interplay of home country and the host country factors including settlement/integration, individual, social, economic and structural factors. In line with an ecological perspective, the thesis introduced a novel conceptual framework (The African Hut Model, see figure 4.1) to theoretically explain the determinants of TB and to guide strategic interventions to eliminate TB among the target group.

The framework provides a new holistic approach to understanding TB burden among Africans living in NZ. As noted in chapter two, the African region has a high TB

burden with prevailing challenges of early diagnosis or undiagnosed TB, which presents a likelihood of extensive latent TB infections within communities. As evidenced in participants' accounts presented in chapter six, the burden of TB and the societal construction of the disease within the country of origin constituted an important determinant of TB incidence in the new country. As an example, previous negative experiences may have engendered the perception that TB is a severe, shameful and deadly disease. Such negative perceptions influence how the disease is "talked about" within the African communities in NZ.

Within the host country (NZ), the model used four metaphors, the door, two windows, and the roof of a hut, to explain the complex interactions that engender the reactivation of TB disease or the acquisition of TB from the host country. These metaphors are used theoretically to conceptualise the dynamic interactions between the factors, as in the case of a hut, and to illustrate how the components impact the vulnerability of the individual who metaphorically lives in this hut to TB.

The underlying principle for this novel model is that complex dynamic interactions occur between several factors at different levels within the environment (systems level) of an individual to influence the incidence of TB. Although the model does not quantify the specific contributions of each component to the occurrence of TB, it provides a useful understanding of the reciprocal interactions between the domains consequently influencing the disease occurrence. It must be emphasised that each component of the model may contribute to the occurrence of TB, however, they are unlikely, on their own, to effectively explain the observed pattern of TB disease. For instance, improving the economic circumstances of Africans alone without a dedicated strategy to address the challenges of the immigration policy, stigma or awareness about available services may not effectively reduce TB incidence. Hence, by embracing

complex mechanisms, the model does not support simple linear mono-causal explanations for TB.

8.1.1 Settlement/Integration Challenges

One important contribution of this study to TB elimination efforts and the general field of migrant health research, is the finding that African migrants faced difficult challenges through the processes of integration or settlement into the NZ environment/society. These difficulties, the study found, may influence Africans vulnerability to developing TB disease from previously acquired latent TB infections or perhaps acquiring TB from their new country. As the epidemiological analysis has demonstrated, over one in five (23.9%) of all Africans with TB were diagnosed within the first year of arrival and more than half within the first five years of arrival (55.3%). The analysis of the interviews further elaborated that the first few years of arrival were the toughest for most Africans. The process of integration or settlement in NZ has been likened to the “door” of the “hut”, which denotes an opening to the opportunities within the new country. Conversely, the same “door” could be shut and, in so doing, lead to the marginalisation of African migrants to the periphery of the NZ society.

Dedicated government programmes and policies such as a comprehensive package for orienting and supporting new African migrants in seeking suitable employment, accommodation, healthcare and other social services could facilitate the wide opening of the “door” and would contribute to minimising the vulnerabilities of new African migrants. For instance, the refugee quota resettlement programmes could be extended to other asylum seekers and new migrants, especially as the composition of the African migrant communities is changing.

One of the strengths of the African communities is their resilience to confronting the challenges of living in their new country. They have formed country/ethnic specific associations, which exist, among other things, to support members. Leaders of these associations could be empowered to partner with government agencies to support new members as they transition into the new society. By empowering the leaders, they could advocate for better services and resources to support their communities. Building and maintaining these partnerships with communities, I argue, will help to address the needs of these communities. It would offer a space for the leaders to self-determine the most important concerns for their new members and serve as social support for both the new and old Africans.

8.1.2 The Socio-Economic Factors

Linked to the difficult settling process is the marginalisation and the inaccessibility of employment opportunities, especially for highly qualified or professional African migrants. The results from the interviews highlighted that many African migrant professionals were engaged in jobs that were dirty, difficult and demeaning (the three D's). These jobs, especially within the first few years, did not only expose people to worksite health hazards, they were also stressful leading to compromised immunity and the likelihood of latent TB infection reactivating. As shown in section 7.3, the 2013 census points to an African migrant population that is largely deprived economically.

The economic factors were denoted on the model by one of the windows of the hut. Metaphorically, the strength of the window would determine the degree of exposure of the individual within the hut to their outside environment. A well-paying job that reflects one's qualifications would influence their physical and mental wellbeing by

shaping food choices, housing, heating and social networks. Conversely difficult economic circumstances would increase the vulnerability of people and, in many instances, limit their interaction with healthcare service providers, as competing demands for other pressing needs such as food and rent push visits to health providers for help down the list of priorities. If the discussion with the executive from the support organisation for persons with TB is any indication, migrants including Africans diagnosed with TB tend to live under harsh economic conditions, in poorly ventilated, cold, damp houses and struggle to pay for power. It further suggests that poor eating habits owing to low incomes might be wide spread within the African communities.

This thesis has argued and demonstrated that, whilst the individual might be exposed to TB before arrival, their living conditions contribute significantly to TB disease developing. This finding advances the application of the ecological perspective of health to TB research by demonstrating that a narrow biomedical focus on the individual biological factors is limiting in understanding and effectively addressing TB among migrants. TB is as biological as it is social. The way it is understood and affects individuals is fundamentally influenced by multiple social forces interacting at different levels within the environment. The application of an ecological framework thus provides useful insights into the complexities that exist and how they may contribute to understanding the incidence of TB.

To eliminate TB among the African migrant community would require dedicated policies aimed at addressing the marginalisation (perceived or real) of this group. For instance, improving housing allocated to quota refugees, supporting asylum seekers/refugees to secure employment, and encouraging and enforcing equal employment opportunities for minority groups. Whilst the government must take a lead role, the African community through its umbrella associations should intensify advocacy for equal employment opportunities. Similarly, these organisations can be empowered to support

their members with skills development trainings by using resources (human) within the communities.

8.1.3 Addressing the Social Factors

Another important contribution of this study to TB elimination and research is that, even in a low incidence country, TB attracts a double stigma. TB may be associated with shame and fear within the community. This may be further compounded by the negative HIV stereotypes transferred to TB. The findings from the study revealed high perceptions of stigma against TB and the notion that, within the African community, TB was perceived as a precursor to HIV. If the discussion with the study participants is any indication, TB within the African community may be hidden, persons with symptoms suggestive of TB may delay in seeking help, and health professionals may face challenges with contact tracing and investigations due to the stigma associated with TB.

The findings from the interviews suggested that the stigma associated with TB was not limited to any specific ethnicity or sub-population, although, as indicated, it was high within close knit communities like those of Africans. The lack of public awareness campaigns on TB contributed to the low perceived susceptibility among the African leaders and the common notion that TB did not exist in NZ. Whilst the low annual incidence rate would not justify a national campaign on TB, I argue that targeted awareness campaigns within vulnerable communities is required if early diagnosis, treatment and elimination is to be achieved. To address TB stigma, health professionals would need to engage with African communities through the existing community structures with interventions aimed at demystifying the myths around TB and to de-normalise the notion that it is a deadly disease. Creating more awareness within the

African communities would help deal with the misconception that TB is non-existent in NZ.

8.1.4 The Structural Factors

The study findings revealed some structural factors that inhibited the accessibility of individuals to TB services. In the novel model, the roof of the hut (model) was used metaphorically to represent the structural factors. These factors, just like the roof of a hut, offer protection to the individuals inhabiting the hut.

The findings suggest that TB was less of a priority for policy makers and did not attract enough financial resources needed by the regional TB team to raise awareness within communities. Whilst community engagement within the African and other migrant communities had successfully led to improved early diagnosis, accessibility of public health nurses to communities for follow ups, and a better understanding of the disease among communities in the past, the analysis showed there had been no awareness campaigns in the past five years. The lack of awareness campaigns may be linked to the misconception that there was no TB in NZ. This misconception may contribute to many Africans with TB delaying in seeking help. As an example, the analysis showed approximately 56.5% of Africans received treatment within three months of the onset of symptoms.

The study further demonstrated that money to pay for an initial GP consultation, lack of awareness about existing health services, weak appreciation of the complex nature of the NZ health system and English language proficiency were significant contributors to delays in seeking help. These factors are the underlying mechanisms that interact to trigger the actual action of individuals and exist independent of our knowledge about them (Bhaskar, 1975; Sayer, 2000). This thesis has argued that influencing individual

intentions alone, without a concomitant action on the underlying structural factors would be inadequate in improving early diagnosis and treatment of TB.

Another important contribution of this study to the field of migrant health research and TB elimination efforts is that the fear of deportation or refusal of a visa by immigration NZ might be instrumental in some African migrants' decision to delay seeking help, abandoning treatment or leaving for overseas, and in some instances avoiding any contact with the healthcare providers. The results revealed a lack of clarity or consistency in the implementation of the immigration NZ policy, as to who gets to leave or stay after diagnosis. Within the communities, the results suggest a lack of information, particularly among new African migrants, about healthcare eligibility and free TB services. There is also a dark box around the link or interaction between healthcare providers and immigration NZ. These grey areas, as identified in the study, creates discomfort among many Africans in seeking help.

Lastly, the study found that there was no national or regional TB elimination policy or strategy with specified targets and dedicated funding. Without specified strategic goals or targets, improvement in services and reduction in TB incidence cannot be demanded. The lack of strategy, I argue, is an indication of a weak political commitment to eliminating TB. It is also the case that, while prominent organisations exist in NZ for other diseases such as HIV and cancers, none was identified by this study as the face of advocacy for TB elimination. The absence of strong advocacy groups suggests TB is unlikely to be elevated to the political agenda, especially as it largely affects migrants who may not have political capital and voice.

8.2 Recommendations

The following recommendations, grounded in the study findings, are proposed to reduce the incidence of TB among African migrants by improving TB prevention, early diagnosis and treatment. The recommendations are categorised under four headings: for policy; practice; research; and for the African migrant community.

Policy

- A national TB elimination strategy with specified goals, targets and dedicated funding streams is required to accelerate the public health action on eliminating TB in NZ.
- A policy on financial support for persons on treatment for TB regardless of their visa status should be considered. This would offer support and relief for individuals already challenged financially, and whose living conditions will further deteriorate because of TB.
- A national programme or strategy to improve accessibility to financial support for migrant start-ups or small businesses, like a migrant business fund, as most may not be eligible for bank loans.
- Clarity in the immigration NZ policy on TB and a clear guide for consistent implementation of the policy is required. Clear information on immigration policy should be widely disseminated at the community level in partnership with existing organisations and their leaders to diffuse the fear of getting diagnosed with TB.
- Support TB prevention and treatment in high burden countries. In doing so, NZ will be contributing to eliminating TB from the world as TB anywhere could be TB everywhere.

Practice

- The regional TB team should consider building a coalition with other relevant organisations and lead the advocacy to get TB elimination high on the political agenda. This will, among other things, lead to improved availability of financial resources for public health action to improve TB services accessibility among migrants.
- Interventions aimed at addressing TB stigma should focus on normalising TB within the community and should include clear communication about the link between HIV and TB to prevent the transfer of negative HIV stereotypes to TB.
- The regional TB team, in collaboration with other partners, should lead the advocacy for improved availability and policies on healthy housing standards, especially for the state houses allocated to refugees and the rental accommodation.
- Actively engage migrant communities to raise awareness about TB and the existing support services available. This would encourage persons with symptoms suggestive of TB to take up services.
- More engagements with media houses to influence and change the national discourse of TB from one of blame on immigration to that which interrogates how living conditions in NZ influences TB acquisition and development among migrants. The regional TB team must be the lead on this.

Community action

- Community leaders in partnership with local authorities, crown agencies and other existing community based organisations should mobilise and empower their members through seminars or talks during regular meetings to improve health literacy.

- Existing African organisations must advocate for more resources to make skills based training opportunities for job search readily available to support the most vulnerable within the community including women and individuals with less or no previous education.
- To facilitate a coordinated action for the improved wellbeing of Africans, the leaders of the various community associations will need to establish a unified platform or a hub (e.g. The African health forum) by drawing on the resources (the diverse skills and professions) within the community. This hub will serve as a source of information on all matters relating to health for the African community and lead all advocacy and/or research for improved health outcomes.
- African community associations must partner with relevant crown agencies to develop a comprehensive welcome package for new migrants. The package must include seminar sessions and an information pack to be widely disseminated within the community.

Research

The following recommendations are submitted for further research:

- A cross sectional survey with an appropriate sample size reflecting the African migrant population should be conducted to understand the determinants of good health in the context of the new country.
- More research is needed to explore the host country factors that contribute to TB among Africans. Future studies in other settings can repeat this study guided by the novel ‘model’ developed from the study findings.

8.3 Concluding Remarks

Overall, the study demonstrated that TB remains an important public health issue, and that NZ may risk missing out on the elimination targets if efforts are not intensified. The findings further indicated that TB disproportionately affected the overseas born (Africans and other foreign born) and those living in the most deprived small areas of NZ (regardless of place of birth). The existing inequities in TB incidence requires public health interventions to increasingly shift from individual centred approaches to addressing the structural, social and economic factors that shape the relatively high rates of TB among the most vulnerable groups. By proposing the novel African Hut Model, the study has offered a framework to explain the dynamic interactions between the existing factors and a guide to practitioners in developing interventions. The model emphasises that TB among Africans cannot be the result of only biological (individual) factors. It is most likely the outcome of the complex interactions between the home and host country factors. The study identified gaps in TB control in NZ including a lack of a national policy and implementation plan for TB elimination. It further highlighted accessibility barriers to TB services. The prevailing silence and lack of advocacy on TB by interest groups may reflect the general society and political perception about the disease – “TB is not a big deal in NZ”. This curable disease, unfortunately, may remain a silent killer afflicting many people even in a developed country like NZ. Eliminating TB would require bold and giant steps that include active engagement of the most affected communities, sustained coordinated advocacy for more resources and effective implementation of evidence based interventions.

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Appendices

Appendix A: Ethics Approval Letters

10 May 2016

Pani Farvid
Faculty of Health and Environmental Sciences

Dear Pani

Re Ethics Application: **16/128 The burden of tuberculosis among Sub-Saharan Africans in New Zealand: The role of individual, social, economic and structural factors.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 10 May 2019.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 10 May 2019;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 10 May 2019 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Kate O'Connor

Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Emmanuel Badu ebadu@aut.ac.nz, Charles Mpofu



Health and Disability Ethics Committees
20 Aitken Street
Freyberg Building
PO Box 5013
Wellington

0800 4 ETHICS
hdec@mh.govt.nz

Tuesday, 3 May 2016

Mr Emmanuel Badu
AR Block
AUT North Campus
90 Akoranga Drive
Northcote
Auckland.

Dear Mr Badu,

Study title: what is the epidemiology of TB including that of African migrants living in New Zealand, and what factors contribute to the relatively high rate of TB among this group
--

Thank you for emailing HDEC a completed scope of review form on 29 April 2016. The Secretariat has assessed the information provided in your form and supporting documents against the Standard Operating Procedures.

Your study will not require submission to HDEC, as on the basis of the information you have submitted, it does not appear to be within the scope of HDEC review. This scope is described in section three of the Standard Operating Procedures for Health and Disability Ethics Committees.

This study wants to answer the question: what is the epidemiology of TB including that of African migrants living in New Zealand, and what factors contribute to the relatively high rate of TB among this group. This study involves semi-structured interviews with participants. Participants will be 15-25 non-vulnerable adults living with TB or recently cured who identify as Africans or close relatives/friends of these people, African community leaders, and Health care workers who work with TB patients. These participants will be recruited by advertisements given by public health nurses (who will be informed of the study by the researcher), publically available information, and advertisements on staff notice boards. No identifiable health information will be used for this study. Interested participants will contact the researcher through contact details on these advertisements. All participants will provide written informed consent.

An observational study requires HDEC review only if the study involves more than minimal risk (that is, potential participants could reasonably be expected to regard the probability and magnitude of possible harms resulting from their participation in the study to be greater than those encountered in those aspects of their everyday life that relate to the study).

For the avoidance of doubt, an observational study always involves more than minimal risk if it involves one or more of the following:

- one or more participants who will not have given informed consent to participate, or
- one or more participants who are vulnerable (that is, who have restricted capability to make independent decisions about their participation in the study), or
- standard treatment being withheld from one or more participants, or
- the storage, preservation or use of human tissue without consent, or
- the disclosure of health information without authorisation.

If you consider that our advice on your project being out of scope is incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

Please note, your locality may have additional ethical review policies, please check with your locality. If your study involves a DHB, you must contact the DHB's research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.

Please don't hesitate to contact us for further information.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Swindells', with a stylized flourish at the end.

Fox Swindells
Advisor
Health and Disability Ethics Committees
hdec@mh.govt.nz



Auckland DHB
Research Office
Level:14
Building: 1 (Support)
Auckland City Hospital
Private Bag 92024
Auckland 1142
Email address:
researchoffice@adhb.govt.nz

11 July 2016

Institutional Approval

Emmanuel Badu
School of Public Health and Psychosocial Studies
AUT North Shore Campus
Private Bag 92006
Auckland 1142

Dear Emmanuel

Re: Research project A+ 7254 The burden of tuberculosis among Sub-Saharan Africans in New Zealand: The role of individual, social, economic and structural factors (AUT 16/128)

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any amendment to study documentation
- Any change to the ethical approval of the study
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee
Dr Mary-Anne Woodnorth
Manager, Research Office
ADHB

c.c. Julia Peters, Pani Farvid

....continued next page

Appendix B: Study Information Sheet



Participant Information Sheet

Date Information Sheet Produced: 10/05/2016

Project Title

The burden of Tuberculosis among Sub-Saharan Africans in New Zealand: The role of individual, social, economic and structural factors.

An Invitation

My name is Emmanuel Badu. I am a PhD student of the Department of Public Health, Faculty of Health and Environmental Sciences, Auckland University of Technology (AUT). I am conducting this research for my PhD thesis. I have chosen this topic to look at ways to reduce tuberculosis (TB) disease rates by finding out about the key factors that are likely to contribute to TB disease among the African ethnicity living in New Zealand.

You are invited to take part in this research and any assistance you can offer me would be greatly appreciated. As part of the project you will be interviewed. The interview process should take a maximum of 90 minutes. The information you give will be used in writing up my thesis and for any publications that would be produced from the thesis. You are under no obligation to participate in the interview. Participation is entirely voluntary. If you agree to participate, but later change your mind, you are free to withdraw at any time before or during the interview process.

How was I identified and why am I being invited to participate in this research?

You were identified through an advertisement as someone who fits the criteria for inclusion in this study. That is, you are above 18 years old, identify as an African (except healthcare workers), and speak English. You are currently on TB treatment or cured of TB, a close relative (family or friend) of TB client, healthcare worker (any ethnicity) who works with TB clients or an African community leader.

What will happen in this research?

You will participate in a face to face interview with me which will last about 90 minutes. The interviews will preferably be audiotaped and transcription done at a later time after the interview, but this would be done only with your consent. The audiotape recording could be stopped or the recorded information withdrawn at any time during the interview process at your request.

What are the discomforts and risks?

I do not anticipate any discomforts or risks to you from your participation in this study. You would contribute to the study by sharing your opinion about TB in a manner that will help improve TB control among the African community.

How will these discomforts and risks be alleviated?

Confidentiality will be ensured at all times and would not need to be uncomfortable in responding to the questions. In the unlikely event that you experience any discomforts in the process, you will have the right to withdraw from the interview or avoid answering any question that you will find unpleasant. You can withdraw from the interview at any time without the need for an explanation.

What are the benefits?

The study offers you the opportunity to contribute to recommendations for TB policies and programmes for the African community. Your suggestions on ways to improve TB prevention programmes will contribute meaningfully to elimination of TB from New Zealand.

Additionally, this research will assist me in obtaining my PhD qualification.

How will my privacy be protected?

Your discussion with me during the interview will be treated confidential and not divulged to any other person. Your name will not be collected during the interview. You will be assigned a code during the transcription which will be used in the thesis or any other publications from the study.

What are the costs of participating in this research?

The interview would last no more than 90 minutes.

What opportunity do I have to consider this invitation?

You have up to two weeks to consider if you would like to participate in the study.

How do I agree to participate in this research?

If you agree to participate in the study, you could contact me to schedule a suitable day and venue for the interview. I would ask you to sign a consent form before the interview is done.

Will I receive feedback on the results of this research?

A summary of the research findings will be sent to you. I will also invite you to attend a presentation on the research findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Dr Pani Farvid, pani.farvid@aut.ac.nz, 09 921 9999 ext. 7326

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Name: Emmanuel Badu

Email: ebadu@aut.ac.nz

Phone: 09 921 9999 ext. 6485

Project Supervisor Contact Details:


Name: Dr Pani Farvid

Email: pani.farvid@aut.ac.nz

Phone: 09 921 9999 ext. 7326

**Approved by the Auckland University of Technology Ethics Committee on 10th May 2016,
AUTC Reference number 16/128**

Appendix C: Participant Consent Form



Consent Form

Project title: The burden of Tuberculosis among Sub-Saharan Africans in New Zealand:
The role of individual, social, economic and structural factors.

Project Supervisor: **Dr Pani Farvid; Dr Charles Mpofu**

Researcher: **Emmanuel Badu**

☐ I have read and understood the information provided about this research project in the Information Sheet dated dd mmmm yyyy.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

☐ I agree to take part in this research.

☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participants signature :
.....

Participant's name :
.....

Participant's Contact Details (if appropriate):
.....
.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 10th May 2016 AUTEK Reference number 16/128

Note: The Participant should retain a copy of this form.

Appendix D: TB Case Report Form

Page 1 of 5

CASE REPORT FORM		Tuberculosis	
Tuberculosis		EpiSurv No. _____	
Disease Name			
<input type="radio"/> Tuberculosis disease - new case		<input type="radio"/> Tuberculosis disease - relapse or reactivation	
<input type="radio"/> Latent tuberculosis infection (patient consent required)		<input type="radio"/> Tuberculosis infection - old disease on preventive treatment (fully investigated and active disease excluded)	
Reporting Authority			
Name of Public Health Officer responsible for case _____			
Notifier Identification			
Reporting source* <input type="radio"/> General Practitioner <input type="radio"/> Hospital-based Practitioner <input type="radio"/> Laboratory			
<input type="radio"/> Self-notification <input type="radio"/> Outbreak Investigation <input type="radio"/> Other			
Name of reporting source _____		Organisation _____	
Date reported* _____		Contact phone _____	
Usual GP _____		Practice _____ GP phone _____	
GP/Practice address Number _____ Street _____ Suburb _____		Town/City _____ Post Code _____ <input type="checkbox"/> GeoCode _____	
Case Identification			
Name of case* Surname _____ Given Name(s) _____			
NHI number* _____		Email _____	
Current address* Number _____ Street _____ Suburb _____		Town/City _____ Post Code _____ <input type="checkbox"/> GeoCode _____	
Phone (home) _____		Phone (work) _____ Phone (other) _____	
Case Demography			
Location TA* _____		DHB* _____	
Date of birth* _____		OR Age _____ <input type="radio"/> Days <input type="radio"/> Months <input type="radio"/> Years	
Sex* <input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Indeterminate <input type="radio"/> Unknown			
Occupation* _____			
Occupation location <input type="radio"/> Place of Work <input type="radio"/> School <input type="radio"/> Pre-school			
Name _____			
Address Number _____ Street _____ Suburb _____		Town/City _____ Post Code _____ <input type="checkbox"/> GeoCode _____	
Alternative location <input type="radio"/> Place of Work <input type="radio"/> School <input type="radio"/> Pre-school			
Name _____			
Address Number _____ Street _____ Suburb _____		Town/City _____ Post Code _____ <input type="checkbox"/> GeoCode _____	
Ethnic group case belongs to* (tick all that apply)			
<input type="checkbox"/> NZ European <input type="checkbox"/> Maori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Maori		<input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Tongan	
<input type="checkbox"/> Other (such as Dutch, Japanese, Tokelauan) *(specify) _____			

Tuberculosis	EpiSurv No. _____
Basis of Diagnosis	
LABORATORY CRITERIA	
Meets laboratory criteria for disease*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Demonstration of acid-fast bacilli in a clinical specimen	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Done <input type="radio"/> Awaiting Results
If yes, specify site	<input type="radio"/> Sputum <input type="radio"/> Other (specify) _____
Isolation of Mycobacterium tuberculosis, or M. bovis from a clinical specimen	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Done <input type="radio"/> Awaiting Results
If yes, specify site	<input type="radio"/> Sputum <input type="radio"/> Other (specify) _____
Demonstration of M. tuberculosis nucleic acid (PCR or LCR only)	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Done <input type="radio"/> Awaiting Results
If yes, specify site	<input type="radio"/> Sputum <input type="radio"/> Other (specify) _____
Histology strongly suggestive of tuberculosis	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Done <input type="radio"/> Awaiting Results
MANTOUX STATUS	
Mantoux tests done*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Awaiting Results <input type="radio"/> Unknown
Date* _____ mm induration* _____ mm	Date* _____ mm induration* _____ mm
Mantoux status* (tick most appropriate - must use definitions in TB guidelines)	
<input type="radio"/> Mantoux Negative <input type="radio"/> Mantoux Positive <input type="radio"/> Mantoux Converted <input type="radio"/> Mantoux Unknown	
IGRA STATUS	
Test done*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Awaiting Results <input type="radio"/> Unknown
If yes, result	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> Indeterminate
OTHER CRITERIA	
Treatment for presumptive TB*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Interim treatment for presumptive LTBI in children < 5 years*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
STATUS*	
<input type="radio"/> Under investigation <input type="radio"/> Probable - presumptive <input type="radio"/> Confirmed <input type="radio"/> Not a case	
(no laboratory confirmation)	(laboratory confirmation)
PREVIOUS HISTORY OF TUBERCULOSIS (relapses or reactivations only)	
Date of first tuberculosis diagnosis* _____	Name of doctor* _____
Place where diagnosis made (town/city/country)* _____	
Was diagnosis confirmed by laboratory testing?*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Was the case treated?*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
If yes, duration of treatment* _____	months
ADDITIONAL CLINICAL DETAILS	
Site of disease (disease only)	
Pulmonary*	<input type="radio"/> Yes <input type="radio"/> No
If yes,	
Radiology*	<input type="radio"/> Normal <input type="radio"/> Active TB <input type="radio"/> TB of Uncertain Activity <input type="radio"/> Not Done <input type="radio"/> Unknown
Evidence of cavity formation*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown

Tuberculosis		EpiSurv No. _____	
Basis of Diagnosis (continued)			
Extrapulmonary* <input type="radio"/> Yes <input type="radio"/> No			
If yes, tick all that apply*			
<input type="checkbox"/> Lymph node (excl abdomen)	<input type="checkbox"/> Pleural	<input type="checkbox"/> Miliary TB	
<input type="checkbox"/> Bone/joint	<input type="checkbox"/> Intraabdominal (excl renal)	<input type="checkbox"/> Renal/genitourinary tract	
<input type="checkbox"/> Soft tissue/skin	<input type="checkbox"/> CNS TB (including meningitis)		
<input type="checkbox"/> Other site, specify _____			
How was case/infection discovered?*			
<input type="radio"/> Contact follow-up		<input type="radio"/> Immigrant/refugee screening	
<input type="radio"/> Other (specify) _____		<input type="radio"/> Attended practitioner with symptoms	
		<input type="radio"/> Unknown	
ADDITIONAL LABORATORY DETAILS (CULTURE POSITIVE CASES ONLY and ESR UPDATED)			
Mycobacterial species <input type="radio"/> <i>Mycobacterium tuberculosis</i> <input type="radio"/> <i>M. bovis</i>			
<input type="radio"/> Other (*specify) _____			
Susceptibility testing results			
Isoniazid (0.1 mg/L)	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Isoniazid (0.4 mg/L)	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Rifampicin	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Ethambutol	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Pyrazinamide	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Streptomycin	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Other antibiotics (specify) _____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
_____	<input type="radio"/> Susceptible	<input type="radio"/> Resistant	
Specimen details			
Date specimen taken _____	Specimen number _____		
Updated <input type="checkbox"/> Reference laboratory _____	Date results updated _____		
Molecular Typing			
MIRU _____	RFLP _____	ClusterID _____	
Updated <input type="checkbox"/> Date Results Updated _____	Specimen Number _____		
Clinical Course and Outcome			
Date of onset* _____		<input type="checkbox"/> Approximate <input type="checkbox"/> Unknown <input type="checkbox"/> Asymptomatic	
Hospitalised* <input type="radio"/> Yes <input type="radio"/> No		<input type="radio"/> Unknown	
Date hospitalised* _____		<input type="checkbox"/> Unknown	
Hospital* _____			

Tuberculosis		EpiSurv No. _____
Clinical Course and Outcome continued		
Died*	<input type="radio"/> Yes	<input type="radio"/> No <input type="radio"/> Unknown
Date died*	<input type="text"/> <input type="radio"/> Unknown	
Was this disease the primary cause of death?*	<input type="radio"/> Yes	<input type="radio"/> No <input type="radio"/> Unknown
If no, specify the primary cause of death* _____		
Outbreak Details		
Is this case part of an outbreak (i.e. known to be linked to one or more other cases of the same disease)?*		
<input type="checkbox"/> Yes If yes, specify Outbreak No* _____		
Risk Factors		
Has HIV test been performed*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
Other immunosuppressive illness (chronic renal failure, alcoholism, diabetes, gastrectomy)*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify _____		
Immunosuppressive medication*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
Contact with a confirmed case of tuberculosis*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify nature of contact* _____		
If yes, did contact occur within New Zealand* _____		
If yes, specify name of case* _____		
Born outside New Zealand*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify country of birth* _____		
If yes, date of arrival in NZ* _____		
<input type="checkbox"/> Unknown		
Current or recent residence in a household with a person(s) born outside New Zealand*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify country of birth* _____		
Exposure in health care setting*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify exposure* _____		
Current or recent residence in an institution (e.g. prison)*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify details* _____		
Exposure to cattle, deer, possums, other wild animals or animal products in work or recreation (<i>M. bovis</i> infection only)*	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
*If yes, specify exposure in detail _____		
Other risk factors for tuberculosis* (specify*) _____		

Tuberculosis	EpiSurv No. _____
Protective Factors	
At any time prior to onset, had the case been immunised with BCG vaccine?*	
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, specify date given* _____ <input type="checkbox"/> Unknown	
If yes, how was this confirmed* <input type="radio"/> Scar <input type="radio"/> Patient/Caregiver recall <input type="radio"/> Documented <input type="radio"/> Unknown	
Management	
CASE MANAGEMENT	
Under specialist care* <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
Name of specialist* _____	
Did the case receive treatment?*	
<input type="radio"/> Yes <input type="radio"/> Treatment declined <input type="radio"/> Treatment inappropriate <input type="radio"/> Unknown	
If yes	
Date treatment started* _____ <input type="checkbox"/> Unknown	
Date treatment ended in NZ* _____ <input type="checkbox"/> Unknown	
Was treatment interrupted?*	
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
Reason treatment ended*	
<input type="radio"/> Tmt completed to the satisfaction of the prescribing doctor <input type="radio"/> Transferred to overseas medical care <input type="radio"/> Went overseas (medical care not transferred or unknown) <input type="radio"/> Died <input type="radio"/> Refused to complete treatment <input type="radio"/> Stopped treatment because of adverse effects <input type="radio"/> Stopped due to pregnancy <input type="radio"/> Lost to follow up <input type="radio"/> Discontinuation of interim treatment for LTBI (child <5 years) <input type="radio"/> Reason unknown	
Did case receive DOT throughout the intensive phase of treatment?*	
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
Did case receive DOT throughout the course of treatment?*	
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
CONTACT MANAGEMENT (disease only)	
Did case have any contacts at risk of infection?*	
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	
If yes, type of contact:	Number Identified
Close contacts*	_____
Casual contacts*	_____
Comments*	

Appendix E: Study Advertisement

Advertisement For Study Participants

AUT

TE WĀHANGA ARONUI
O TĀMĀKĀI MĀKAU RAU

Dear Sir/Madam,

My name is Emmanuel Badu. I am conducting this research for my PhD programme at the Department of Public Health, Faculty of Health and Environmental Sciences, Auckland University of Technology (AUT). The aim is to look at ways to reduce tuberculosis (TB) disease rates by finding out about the key factors that are likely to contribute to the occurrence of TB disease among the African ethnicity living in New Zealand.

I am seeking Africans currently on treatment for TB or treated for TB in the past four years in New Zealand, a friend, a relative or family member of someone with TB or treated for TB in the past four years to interview as part of the project. The interview process should take a maximum of 60 minutes and you will be given a token gift to compensate you for your time and contribution to the study. Participation in this study is entirely voluntary. If you agree to participate, but later change your mind, you are free to withdraw at any time before or during the interview process. Your personal details and any findings which could identify you shall not be collected. Your privacy and confidentiality shall be protected at all stages of the research.

You are invited to take part in this research and any assistance you can offer me would be greatly appreciated. The study offers you the opportunity to contribute to recommendations for TB policies and programmes for the African community.

If you are currently on treatment for TB, treated for TB in New Zealand in the past four years, a friend to someone with TB now or in the past, and a family or relative of someone with TB, and would like to be part of this study, kindly contact me via email, text, WhatsApp, Viber or phone on the contact details below. I am happy to contact you back as soon as I hear from you.

Thank you.

Approved by the Auckland University of Technology Ethics Committee on 10th May, 2016,
AUTECH Reference number 16/128.

TEAR OFF SLIP WITH MY NUMBER

02108733491 ebadu@aut.ac.nz	02108733491 ebadu@aut.ac.nz	02108733491 ebadu@aut.ac.nz	02108733491 ebadu@aut.ac.nz	02108733491 ebadu@aut.ac.nz
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Appendix F: Interviews Question Guide

Question Guide – Community Leaders

1. Can you please tell me about yourself? Like where are you from, what do you do for a job and how long have you been in NZ?
2. What to you are the differences in life in Africa and NZ?
3. How is settling in NZ like for Africans?

Personal factors

1. Firstly, I'd like to ask you some general questions about what you know about TB. This isn't a test, I'm just interested in your perspective:
 - a) What do you think causes TB?
 - b) What do you think are the symptoms of TB?
 - c) How do you think it can be passed?
 - d) Do you know of any ways transmission might be prevented?
 - e) Do you know how TB usually gets treated?
 - f) Do you ever consider yourself as at risk of getting TB? (how, why, when)
 - g) Where have you got all this information about TB from?
2. What do you think might be a good way to provide people in your community with information about TB?

Social factors

Now I want to ask you some general questions about how people in your community perceive TB:

- 1) Do people in your community know what TB is?
- 2) How do they perceive it? What do you think they think of it?
- 3) If a person is diagnosed with TB – how do you think they are treated in your community? Why do you think that is?
- 4) Do you think the treatment is different if people are family, friends or acquaintances?
- 5) How are people with TB usually talked about?
- 6) If the notion of stigma comes up – ask – do you think the way TB is stigmatised affects how people with symptoms might react?
- 7) How do you think this stigma might affect people in other ways?
- 8) Are you aware of any support that persons who have TB receive?

Economic factors

- 1) Please are you aware of any costs that persons diagnosed of TB have to bear?
- 2) In your own opinion how can TB impact on employment status of persons living with TB?
Probe: any stories to share?

- 3) What challenges do you know of that persons who have completed TB treatment are faced with in securing a job?
- 4) How would you describe the general living conditions of African migrants living in NZ? Probe: what about that of African TB patients?

Structural factors

- 1) How are African migrants with TB treated by their doctors or other healthcare professionals?
- 2) How do they adhere to their treatment?
 - a. Are there any support systems that help them?
 - b. Are there any challenges they face?
- 3) What do you think are the main barriers to TB treatment services among your community?
- 4) What are the main (common) concerns of African migrants with TB, their family and the community on TB prevention programmes in NZ?
- 5) What can you, as a community, do about these? What would you want done about these?
- 6) What about NZ immigration policy – do you think this influence how TB is understood or treated?
- 7) Are there any other concerns you would like to share to improve the health of African migrant communities?
- 8) Is there anything else you would like to add?

Question Guide – HealthCare Professionals

I'd like to ask you some general questions about the services you provide to your clients with some emphasis on your African clients. This isn't a test, I'm just interested in your perspective

Can you please tell me about yourself? Like where are you from, what do you do for a job and how long have you been doing this?

- 1) Please describe for me the services available for people with TB.
- 2) What costs do people with TB incur?
- 3) How is it like for you in your first encounter with Africans with TB?
- 4) What are the common (main issues) in your first encounter with them?
- 5) What about in the course of the treatment, do any issues emerge?
 - a. How do your clients manage these?
- 6) What are the main (common) concerns for you, in dealing with Africans with TB, their family and the community?
- 7) What are the main (common) concerns for your African clients?
 - a. How can this be addressed?
- 8) In your opinion how does stigma associated with TB within the African community affect TB patients?
 - a. Probe: how about you, your work within the African community?

- 9) What do you think are the main barriers to TB services among this community?
- 10) What about immigration policy, how does it influence TB treatment?
- 11) How would you describe the general living conditions of your Africans with TB?
- 12) Are there any other concerns you would like to share to improve the health of African migrant communities?
- 13) Is there anything else you would like to add?

Appendix G: Thematic Analysis Coding Tree

