

### **Researching the Prevalence of Tuberculosis in Marginalized Populations:**

A Socioeconomic Analysis of Black South Africans and Canadian Indigenous populations

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Historically, tuberculosis has thrived in some of the most impoverished and marginalized populations; however, research into why lower socio-economic populations are at a higher risk of contracting disease lacks exploration. This is becoming a more prevalent issue as multi-drug resistant Tuberculosis (MDR-TB) and extensively-drug resistant Tuberculosis (XDR-TB) are on the rise in individuals living in poverty. South Africa is an important area of focus because of its long history of racial discrimination. Consequently, black populations in South Africa are disproportionately affected by poverty and disease. Connections between tuberculosis and poverty will be critically analyzed in a South African context by reviewing the existing literature and government documents, including those by Statistics South Africa and the World Health Organization. A cross-cultural comparison to Canadian Indigenous populations highlights the long-term effects of marginalization and societal stratification. Health care policies dealing with treatment are also discussed, with a specific focus on social epidemiology. This paper argues that long-term racial inequalities in South Africa have resulted in economic disparity, through which Black Africans are most susceptible to contracting TB, MDR-TB, and have insufficient health resources to support them.

#### Introduction

In 2014, the World Health Organization (WHO) introduced the End Tuberculosis (TB) Strategy, a plan designed to reduce TB deaths by 90% and incidence rates by 80% by 2013 (WHO, 2016). Despite this call, the TB epidemic is far from over; in 2015, this infectious disease directly resulted in 1.4 million deaths and 10.4 million new cases worldwide (WHO, 2016). Previous to this, TB had been considered a historical disease; Schatz and Waksman developed the first effective course of antibiotics to treat TB in the mid 1940s (Gomez & McKinney, 2004). However, shortly after treatment options became available and incidence rates of TB began to decrease, cases of

drug-resistant TB were reported (Espinal, 2003). In recent years, there has been a resurgence of TB that poses a serious global health challenge. New strands of TB are emerging that are resistant to the treatments available. Countries such as South Africa are increasingly reporting cases of multidrug resistant TB (MDR-TB), extensively-drug resistant TB (XDR-TB), and HIV-TB coinfection. This is especially problematic in countries with low socio-economic status, as TB has been associated historically with high levels of poverty (Spence, Hotchkiss, Williams, & Davies, 1993). South Africa has one of the highest incidence rates of TB, and particularly of HIV-TB coinfection, globally (WHO, 2016). South Africa's political, economic, and social history

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contributed to the increased prevalence of TB in this country. Marginalized and impoverished communities are most impacted by TB in South Africa as a result of institutionalized and systematically enforced racial inequality (Myer, Ehrlich, & Susser, 2004). Many afflicted individuals lack access to healthcare facilities or the financial means to receive treatment. This paper explores the role that socio-economic inequalities play in rising incidence rates of TB in South Africa, arguing that long-term racial discrimination has resulted in economic inequality and limited access to healthcare for black South African populations. A cross cultural comparison is drawn with Canadian Inuit populations to further illustrate how colonization and systemic racial inequalities drives both poverty and TB rates, and to highlight that this phenomenon is not isolated to South Africa.

#### Background

*Mycobacterium tuberculosis* is an airborne bacterium that primarily attacks the lungs, but can also be present in other parts of the body (as extrapulmonary TB). Individuals at risk of contracting TB are primarily those living in proximity to an active infectious source, or those living in overcrow

ded areas (Coberly & Chaisson, 2001; Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). Pre-existing conditions like HIV-coinfection and malnutrition may increase an individual's chances of contracting TB or encourage the progression of disease following infection, making individuals more susceptible to TB infection (Lönnroth et al., 2009). In five to ten percent of people TB symptoms present soon after infection, which is known as primary illness (Centers for Disease Control and Prevention, 2014; Harling, Ehrlich, & Myer, 2008). However, the infection can also remain latent in the body with no initial symptoms for years before reappearing; this is known as reactivation illness (Harling et al., 2008). When the disease becomes active in the body, an extensive treatment of multiple antibiotics over six to twenty months is necessary to successfully eradicate the infection, and consequently it can be costly to treat. Without treatment, death rates from TB are high. Before effective medications became available in the 1940s, 70% of individuals with active TB died within 10 years (WHO, 2016). This is particularly problematic in impoverished areas where access to medication and health care is limited. Social, economic, and environmental factors are key to the bacterium's success in a population, and as such it has been labelled a "social disease" or a disease of poverty (Lönnroth et al., 2009, p. 1; see also Harling et al., 2008).

Rates of poverty in South Africa are high amongst marginalized populations (Statistics South Africa, 2017). Rates of TB in these populations are also consistently higher than in non-marginalized populations (Harling et al., 2008). This paper will use the terms black, white, Coloured, and Indian to refer to populations in South Africa, as this is how many South Africans categorize themselves post-Apartheid (Seekings, 2008). Coloured is a term that both historically and currently refers to individuals with both white and black ancestry (Goldin, 1987; Seekings, 2008). From 1948 to 1991, South Africa was racially segregated by Apartheid, a legal system that favoured white people over black, Coloured, or Indian individuals. South Africa's historical legacy of institutionalized social inequality corresponds rates in marginalized with increased TB populations. Marginalized classes have less access to healthcare professionals, are unable to afford TB medication, or to consistently treat it, and have greater exposure to conditions that increase TB transmission, such as living in close quarters (Lönnroth et al., 2009). Another significant factor that plays into this is rates of HIV-TB coinfection. The WHO (2016) identifies that the proportion of individuals receiving treatment for TB and also living with HIV accounts for 45% of total TB rates.

TB health initiatives in South Africa are ambitious, and the country is currently

implementing the WHO's plan to end TB by 2030 by successfully diagnosing and treating at least 90% of all notified TB cases. Despite this, many patients are unable to follow up with treatment due to a failure of adequate social systems in communities (Kigozi, Heunis, Chikobvu, Botha, & van Rensburg, 2017). From 2003 to 2011, 6.1% to 11.2% of TB patients withdrew from treatment, while successful treatment outcomes from 1995 to 2011, ranging from 58% to 79%, fell short of the 90% goal (Kigozi et al., 2017). Even more concerning are the results of Gandy and Zumla (2002), which suggest that only 15% of patients worldwide receive adequate TB therapy.

Poverty plays an important role in the spread of TB. Factors such as restricted access to healthcare, overcrowding, and food insecurity contribute to the risk of contracting TB (Lönnroth et al., 2009). As such, poverty is an important concept to examine as its relationship with TB is explored further. When referring to poverty and impoverishment, this paper utilizes the five dimensions of poverty proposed by Chambers (1988). These five dimensions effectively capture the complex of social features that are tied into poverty (Table 1).

Dimension	Features or Consequences
Poverty Proper	A lack of income and assets
Physical	A result of malnutrition,
Weakness	disability, or illness
Isolation	Refers to physical and social isolation that may prevent an individual from accessing services, including healthcare
Vulnerability	Individuals may be at a greater risk of becoming poorer
Powerlessness	Individuals do not hold significant standing in society

*Table 1*. Five Dimensions of Poverty (after Chambers, 1998)

In addition, the use of social epidemiology is applied throughout this paper, as it is a model that directly looks at how social conditions and interactions affect the health and wellbeing of individuals. Kawachi and Berkman (2001) define social epidemiology as the distribution and determinants of health, analyzed through individual and community social conditions. This theory views an individual's risk of becoming ill as being determined by their biology and their position in society (Kawachi & Berkman, 2001). Social structures that are considered within this model are social class, gender, ethnicity, discrimination, social network, social policy, and income distribution (Honjo, 2004).

# The Long-term Effects of Racial Inequality in South Africa

From 1948 to 1991, South Africa was racially segregated by Apartheid, a legal system that favoured white people over black, Coloured, or Indian individuals (Williams et al., 2008). Although the extreme institutionalization of racism is unique South Africa, to the characteristics it embodied stemmed from colonialist attitudes, wherein white individuals were considered to be superior to others. The laws were put in place to protect the political dominance and economic positions of privileged white people, and to ensure racial purity or inhibit the "mixing" of "white blood" (Seekings, 2008, p. 3). Discriminatory social norms reinforced by the laws of Apartheid prevented black individuals from getting a high quality education (from institutions that were inherently racially discriminatory and partial to white individuals), or high paying jobs, and they were removed from their homes and made to live in overcrowded areas designated just for black people (Seekings, 2008). Today, post-Apartheid South Africa is shaped by economic, social, and political racial roles (Seekings, 2008). Following Apartheid, most white South Africans remained privileged, while many black South Africans remained poor

(Seekings, 2008). There has been growth in the black upper and middle classes, mostly due to the de-racialization of education and in the labour market, as well as post-Apartheid policies that favour black populations (Seekings, 2008). Consequently, this rapid growth pushed many black individuals further into poverty (Seekings, 2008).

This long-term history of discrimination underlies all variability and inequality in income and health in South Africa. Generally, white South Africans have remained wealthier, while black South Africans are still poorer (Seekings, 2008). In 2015, poverty rates in South Africa increased after years of stability, with 55.5% of the population reportedly living below the poverty line (Statistics South Africa, 2017). Black South Africans have consistently remained the most impoverished population in South Africa, with poverty levels of 47.1% in this group in 2015 (Statistics South Africa, 2017), followed by Coloured people, Indian and Asian peoples, and white people with the lowest rate of poverty at just 0.4% (Statistics South Africa, 2017). These statistics indicate clear inequalities between ethnic groups.

Statistics also show that TB rates are higher in black populations than in white populations. In 1996, the government of South Africa and the WHO published a Joint Programme Review that detailed the prevalence rates of TB by racial group within the population (Figure 1).

One theory suggests that high prevalence rates of TB in Black populations can be attributed to a lack of immunity to the bacteria, which was introduced by early white colonialist settlers (Packard, 1989). The acceptance of this theory alone promotes a racially segregated ideology that disregards the significant contribution that discrimination has had in the current economic situation and health of Black South Africans. This theory coincides with "eugenics" ideology, wherein TB infection removes 'degenerates' from the human gene pool (Mason, Roy, Spillane, &



*Figure 1*. Prevalence rates of TB by racial group in South Africa. These are the most recent data published that clearly identify the rates of TB by racial group in South Africa (data taken from WHO, 1996)

Singh, 2015, p. 210). This theory ties into colonial attitudes that consider white individuals to be superior to those of other ethnicities. Arguably, marginalization of black individuals in South African society perpetuates inequalities in healthcare by restricting their access to healthcare facilities, and to the funds they need to support themselves while receiving treatment.

#### **Economic Burden of Tuberculosis**

Despite the fact that TB is an entirely treatable infectious disease, many individuals lack the resources necessary to access treatment. Until 2016, the WHO recommended a 20-month treatment plan that cost about \$2,000-\$5,000 USD per person (WHO, 2016). More recent drug regimens suggested by the WHO cost about \$1,000 USD (WHO, 2016). In 2008, the per capita income of black Africans was an average of R 9,790 (\$1, 457 USD), while white populations made an average of R 75, 297 (\$11, 205 USD) (Leibbrandt, Woolard, Finn, & Argen, 2010). Low-income countries rely on international donors for nearly 90% of their financing to support TB treatment programs (WHO, 2016). In 2016, funding for low and middle income countries was \$2 billion USD short of the \$8.3 USD needed, and the gap will only increase if funding does not increase (WHO, 2016). In South Africa, the national TB budget is \$244 million USD (WHO, 2016). 90% of this is domestic funding, while the remaining 10% comes from international funding (WHO, 2017).

Foster et al. (2015) report on personal costs that individuals incur while seeking treatment for TB. They highlight the direct costs of TB treatment, which include costs of transportation to and from doctor's appointments, as well as costs for medication, or for consultation while seeking care (Foster et al., 2015). These factors, which are most relevant during pre-diagnosis and diagnosis, account for the largest share of costs during TB treatment. Indirect costs of treatment include income lost while seeking medical care, or

through sick days, long-term leave. or unemployment due to illness (Foster et al., 2015). Additional costs include nutritional supplements, for those living with HIV-TB especially coinfection who have an underlying immunosuppression that decreases the body's ability to protect itself from bacterial infection. The greatest expenses incurred while seeking treatment are costs associated with finding another individual to take over missed work, to look after an ill individual, and to accompany the individual to health facilities. This study highlights the financial, and social challenges personal, individuals face when treating TB. Although TB medication in South Africa is funded by the government, there are social factors that must be in place to ensure completion of treatment, including ensuring household financial stability. Readily available social support structures are a key component to successfully completing treatment without being pushed further into poverty (Foster et al., 2015). This includes interest-free money lending services, and the availability of people to take over jobs and household chores for individuals that are no longer able to work (Foster et al., 2015).

Due to high rates of HIV-TB coinfection, many individuals must also seek medical care for HIV. Like TB, the cost for treatment for HIV is funded by the government; however, most costs are incurred while traveling to visit the doctor, as well as the fee to see the doctor (Rosen, Ketlhapile, Sanne, & Bachman DeSilva, 2007). When beginning HIV treatment, the average person travels to the doctor at least six times, with estimated costs at R 120 (\$8.79 USD, based on 2017 rates) per visit (Rosen et al., 2007).

The cost of seeking medical treatment for TB in South Africa can greatly exacerbate pre-existing financial issues, and can push families further into poverty. This phenomenon is known as the "medical poverty trap", and is an increasingly significant issue worldwide (Whitehead, Dahlgren, & Evans, 2001, p. 833). Whitehead et al. (2001) identify four main repercussions of the medical poverty trap. The first is untreated morbidity, a result of social factors that inhibit poorer individuals from receiving treatment (Whitehead et al., 2001). This is an issue in both low and high income countries. For example, Brudney and Dobkin (1991) note that poverty and social deprivation were responsible for increasing incidence rates of TB in New York. Secondly, the medical poverty trap reduces access to care (Whitehead et al., 2001). Countries that introduce fees to access healthcare will only increase revenue slightly, and will greatly limit the number of people who are able to access medical professionals. Individuals are then likely to avoid attending a health clinic until there is an emergency, and they will usually spend more money once this happens. The third repercussion is long-term impoverishment (Whitehead et al., 2001). Medical expenses are unexpected, necessary, and can be damaging for families. The cost of healthcare can result in debt via loans required to pay for necessary treatments, with high interest rates each month. Whitehead et al. (2001) note that people may compensate for medical expenses by reducing food costs. The irrational use of drugs is the final repercussion of the medical poverty trap. This includes overprescription of medication and consequent drug resistance from pathogen exposure to medications incomplete during treatment regimens. countries' Increasingly, low-income health workers profit from the sale of pharmaceuticals, and this acts as an incentive to prescribe more to patients. For example, in Vietnam, it was reported that 67% of all people who had experienced illness in the previous four weeks had acquired prescriptions for medications without first seeing a doctor (Whitehead et al., 2001). Consequently, there has been a significant increase in drug resistance in Vietnam. The ramifications of expensive and inaccessible medical care are significant, and yet they are often overlooked. Poor populations receive ineffective treatments that can cause long-term repercussions to their health; if individuals can only afford part of the

treatment, as is often the case for TB, it renders the medications ineffective and creates a resistance to the drugs as the disease no longer responds to the medication (Whitehead et al., 2001).

# Canada and Tuberculosis: A Cross-Cultural Comparison

Canada has one of the lowest rates of active TB worldwide, with as few as 1,630 active cases per year (Gallant, Duvvuri, & McGuire, 2017). The enforcement of strict health policies and accessibility of healthcare for most of the population has helped to keep TB rates stable over the last 10 years. Although incidence rates are declining in Canada, TB is found mainly in marginalized populations, a feature that is shared with low-income countries (Aho et al., 2017). Studies indicate that Indigenous populations and migrants from countries where TB is endemic disproportionately account for active cases (Aho et al., 2017; Gallant et al., 2017). Indigenous populations in Canada represent only five percent of the overall population, but are responsible for 50% of TB cases (Eisenbeis et al., 2016). Often, individuals that are homeless, incarcerated, abuse substances, or who are coinfected with HIV/AIDS are more susceptible to TB (Aho et al., 2017).

Canadian colonialism was characterized violence. Settlers historically by removed Indigenous peoples from their homelands and introduced residential schools, both of which perpetuated "cultural genocide" (Davis et al., 2017, p. 399). Parallels between Indigenous populations in Canada and black South African populations illustrate how colonization and marginalization have impacted the health and mortality of these individuals. In both Canada and South Africa, the effects of colonization and societal stratification are still present today, and advancements toward aiding low-income citizens have been slow to develop. Historically, Canadian Indigenous populations were subject to years of racial discrimination as a result of colonization. In

Canada, many Indigenous populations today are subjected to lower standards of living than non-Indigenous populations (Stephens, Nettleton, Porter, Willis, & Clark, 2005). They struggle with poor living conditions that leave them susceptible to infectious disease, in combination with low access to fresh food and health services (Gracey & King, 2009). The long-lasting effects of colonization have left Canadian Indigenous peoples living on unproductive land, and in rural slums and camps that are contaminated by metal and industrial waste (Gracey & King, 2009). As a result, Indigenous populations suffer inequalities in health and emotional wellbeing, with poor prospects for future generations (Gracey & King, 2009).

Canadian treatment strategies differ greatly from those used in South Africa. After World War II, the Canadian government began to address increasing rates of TB in Indigenous populations in Nunavut. As a response, affected Inuit were sent to southern areas of Canada for treatment, often being separated from family who were unaware of their condition or location (Møller, 2010). This represented a shift in healthcare in which Inuit began to lose control of their own health and wellbeing and were forced to adapt to Euro-Canadian models (Møller, 2010). Other cultural changes that were previously implemented in Indigenous communities to integrate them into European culture included the introduction of Euro Canadian schooling, dependence on store-bought food, and the introduction of non-Indigenous individuals to communities that maintained control over Indigenous life (Brody, 2000; Tester & Kulchyski, 1994). These cultural changes, both historically and currently, have contributed to a lower standard of living. This can be seen in Nunavut, where access to healthcare is limited, and the recruitment of doctors into communities is difficult (University of Ottawa Medical School, 2017). Those who require advanced treatment must leave their communities for extended periods of time (University of Ottawa Medical School, 2017). Food security is another problem in Indigenous communities, due to the higher prices of healthy foods (University of Ottawa Medical School, 2017). Additionally, Statistics Canada (2015) reports that 25% of Inuit live in overcrowded households that required major repairs. Restricted access to healthcare, food insecurity, and poor housing conditions have been linked to the spread of infectious disease, as well as of respiratory tract infections more specifically (Inuit Tapiriit Kanatami, 2007).

Today, the prevalence of TB cases is consistently higher in Inuit populations than in any other population in Canada. Inuit incidence rates of TB are 157.7 per 100,000 people, while incidence rates in non-Indigenous populations are 0.8 per 100,000 (University of Ottawa Medical School, 2017). High rates of TB in Indigenous populations can to some degree be attributed to a lack of biological immunity; however, it is more likely that these high prevalence rates are the long-term consequence of colonization and racism, which have impacted the overall health of Indigenous populations and fostered environments in which TB can thrive.

#### Alternative Public Health Initiatives

Currently, public health initiatives in South Africa are unable to cope with increasing incidence rates of TB. Additional pressure from MDR-TB, XDR-TB, and HIV-TB coinfection have slowed the process of providing TB treatment for infected individuals. Globally, there is a lack of funding for TB, which fell \$2 USD billion shy of its target to effectively treat TB in 2016 (WHO, 2016). Although this on its own poses a major problem, it is further exacerbated by social and economic factors that influence an individual's ability to pursue medical help. Based on the research cited here, there are some proposed adjustments that would aid in slowing incidence rates of TB in South Africa. Mostly importantly it is crucial that support and healthcare facilities are readily available in communities. Government focus

should shift to aiding families financially while they pursue medical treatment, as well as providing aid to cover additional costs associated with income loss due to work missed while ill or while seeking treatment. This would encourage individuals to seek treatment, knowing that there will be no financial repercussion. The benefits of this strategy would be three-fold. First, the number of people receiving TB treatment would increase dramatically, and there would be fewer instances where people would have to stop treatment before it was completed. Secondly, there would be a decrease in drug resistance and a lower risk of becoming ill with either MDR-TB or XDR-TB, as resistance to drugs is a consequence of inconsistent treatment. Finally, offering rapid HIV testing while individuals seek medical help would be beneficial in a country where rates of both infections are high. Individuals with suppressed immune systems are more susceptible to contracting TB, and, as such, targeting both would help HIV/AIDs efforts, and would also help public health officials in treating new TB patients. Ultimately, these solutions suggest a path in which the risk of a medical poverty trap is greatly reduced.

In the Canadian province of Quebec, a series of laws are in place to effectively deal with the treatment and prevention of TB. This provides an example of an effective system that could be implemented for other countries to reduce incidence rates of TB. By law, all cases of TB in Quebec must be reported (Aho et al., 2017). Pursuing treatment of active TB is mandatory, and laws are in place to ensure that individuals are in compliance with this (Aho et al., 2017). The Public Health department follows up with individuals until treatment is completed and a negative is result is reached (Aho et al., 2017). Enforcing laws that encourage individuals to pursue treatment and complete it would greatly reduce individuals' risk of acquiring MDR-TB and XDR-TB, decrease chances of death, and decrease the risk of spread of infectious diseases.

There are some notable limitations in applying a Canadian example to a South African healthcare context that should be addressed. First and foremost, there may be different policies in place in Canada that protect the rights of individuals who are poorer and are reluctant to miss work to see a doctor. This could possibly be covered under paid sick or personal days. Additionally, the Canadian government may cover costs to see a doctor, as well as costs of transportation. Secondly, to ensure that individuals living in poverty are not further pushed into poverty or criminally charged for failing to receive treatment, there should be protective barriers in place. This may include providing additional support to individuals, or temporary probation until treatment is successfully completed. It is important that there would be no lasting criminal charges or fines issued that may further push individuals into poverty, or potentially hinder their chances of being employable. These are essential elements to consider when applying this model to South African health policies.

#### Conclusion

This research suggests that long-term racial inequalities in South Africa underlie variability in both economics and health. Current racial discrimination, embedded through centuries of colonialist policies and reflected in current poverty rates, is affecting TB incidence in this country. Black South Africans and Coloured peoples are disproportionately affected by poverty, TB infections, and HIV-TB coinfection. This can be attributed to social conditions in impoverished communities, which lack the resources necessary to aid individuals seeking treatment, especially in terms of financial compensation. The economic burden of TB for families living in poverty is difficult to manage, and can discourage them from pursing necessary treatment. Individuals incur costs while seeking a doctor, as well as from missing work while at the doctor's office, or from being too ill to work. This pushes families into the medical poverty trap, a

result of increasing out-of-pocket health expenses that could be avoided with adequate social support networks in place. Arguably, one of the biggest policy changes that should be made is providing household financial support to individuals that are receiving treatment for TB. Covering costs for missed work and transportation to and from a doctor would ensure that individuals are treated and cured, but would also greatly decrease the chances of drug resistance, reduce the risk of spreading disease, and would lower overall TB incidence rates in South Africa. As well, this may help individuals with HIV-TB coinfection begin to receive proper treatment and care. The high incidence of TB in South Africa is the result of a gross economic disparity that favours white individuals and hinders black South Africans; however, with the proper funding, social services, and external aid it is possible to begin reducing TB rates.

These arguments are bolstered by evidence from the Inuit population in the Canadian province of Nunavut, which is disproportionately impacted by TB compared to the rest of the Canadian population. The disparities between Canadian Indigenous and non-Indigenous populations are a result of colonialism and systemic racism engrained in society. Enforcement of Euro-Canadian culture into Indigenous lifestyles contributed to a lower standard of living. limited including access to healthcare professionals, food insecurity, and poor quality housing. Parallels can be drawn between Canada and South Africa to demonstrate how marginalization and discrimination have lasting effects on a population's health and overall wellbeing. This comparison is particularly useful in highlighting the effects of TB on populations experience marginalization and that discrimination, in which a high incidence of TB does not result from biological susceptibility, but is rather a result of the societies in which these individuals live.

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