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Effects of Racial Identity, Socioeconomics, and Stigma on the Experience of Those Effected by Leprosy in Minas Gerais, Brazil

by

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An abstract of a thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Global Health 2019

Abstract

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By Bailey Conner

Brazil has the second highest rate of leprosy, worldwide, and incidence has had no significant decrease in recent years. Novel insight, approaches, and perspectives to the issue are necessary to address this disease. Perceptions of racial identity, socioeconomics, and stigma are often overlooked in colloquial discourse regarding those affected by leprosy. This project intended to assess the role sociocultural factors in patient's experiences with leprosy. Ultimately, these findings could contribute to an improvement in patient care, treatment options, and policies impacting those living with leprosy. A series of twelve interviews and three oral histories were conducted at a clinical diagnostic center, Hospital Eduardo de Menezes, and former leprosarium, Santa Isabel; both in, and around, the city of Belo Horizonte, Brazil. Interviews focused on, but not were not limited to, topics such as perceived racism, experiences with providers, experiences of socioeconomic factors affecting access to care, and effects of stigma when accessing care. Participant responses highlighted that their experiences were collectively shaped by their racial identity, income, and stigma. Race was expected to have a much more profound effect on patient experience, but this was not the case. Across all participants, socioeconomics and primarily stigma, had much more impactful effects on patient experiences. While the largest amount of respondent variation occurred between those treated within the colony and those treated as outpatients, perception of stigma appeared across the board as having a negative effect on patient experiences. A heightened focus on addressing leprosy-related stigma among clinicians and locals would enhance medical training, improve patient and provider experiences, and ultimately reduce stigma against those affected by leprosy. Additionally, novel and intersectional approaches to leprosy—specifically combining biological and sociocultural focuses—are needed to bolster the narratives of those affected, and ultimately improve control and treatment.

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Chapter 1 Introduction:

Introduction and Rationale

Leprosy, also known as Hansen's disease (HD) is a chronic infectious disease that mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes (Neglected Diseases in Brazil, n.d). The disease is curable, and early treatment can prevent long term damage and disability. It has long been considered a highly contagious and devastating disease, but it is not easily transmitted and it is treatable with multidrug therapy (MDT) (WHO, 2016). Even with this information, new cases of leprosy continue to present in Brazil, which holds the distinction of having the second largest burden of the disease in the world (WHO, 2016). Specifically, areas in Minas Gerais near Governador Valadares have a particularly high incident rate of leprosy. Unfortunately, global annual case detection rates have not declined in more than a decade despite the availability of multidrug therapy to all countries by the World Health Organization (Penna, 2007). Additionally, and of most importance to this project, stigma, racism, and low socioeconomic status have additionally slowed efforts to effectively control the infection (White, 2007).

Leprosy has been a public health problem in Brazil for hundreds of years. While leprosy is thought to have been introduced to Brazil in the late sixteenth century, anti-leprosy initiatives did not begin until the 1920s, according to the International Leprosy Association (ILA) (2019). By 1927, the intervention strategies in Brazil consisted of the methodical isolation of infected individuals (ILA, 2019). The World Health Organization (WHO) describes leprosy patients as being "ostracized" by their communities throughout history (2019), which suggests that these efforts may have resulted in increased leprosy stigma and human rights violations.

Within Latin America, Brazil accounts for a large proportion of Neglected Tropical Diseases (NTDs), including leprosy (Marins-Melo et al., 2011). From 2000 – 2001, approximately 3,000 individuals died of complications from leprosy in Brazil (WHO, 2016). This accounted for almost 4% of mortality from NTDs in Brazil (Penna, 2017). In addition to mortality, leprosy has a large burden for disability, all exacerbated by barriers to care such as race, socioeconomic level, and/or education. Leprosy affects the nerves, skin, eyes, and lining of the nose. The disease, if left untreated, can manifest in many ways including loss of sense of touch and pain, which can lead to injuries, such as cuts and burns (CDC, 2017). Additionally, the nerve damage can result in paralysis of hands and feet. Additionally, corneal ulcers and blindness can occur if facial nerves are affected (CDC, 2017). These disabilities affect patients' abilities to live their lives and work. They also create a stigmatizing and often ostracizing effect as they present physical manifestations as well.

Perceived discrimination is related to poor health and has been offered as one explanation for the persistence of health inequalities in some societies (Mackino, 2012). Discrimination is believed to contribute to poor mental and physical health through several pathways, including structural factors such as unequal access to and treatment in social services such as healthcare (Bastos, 2010). Additionally, leprosy-associated stigma remains an issue with accessing appropriate health care for leprosy, which in turn can lead to more stigmatizing manifestations of the disease.

Addressing the burden of leprosy in Brazil will directly tie into the WHO aims to provide universal health coverage to the vulnerable population of Brazil. It will make a contribution to reaching Sustainable Development Goal 3 – reaching health and wellbeing for all by 2030. There are considerable gaps in knowledge regarding leprosy transmission and diagnosis and practically no research on the intersection of race, socioeconomics, and stigma in Brazil. The findings of this study will expand understandings of the disease and these participants experience. Additionally, they will provide opportunity for expanding knowledge that can ultimately result in an improved, more culturally and socio-contextually appropriate understanding of the disease and subsequently improved approaches to treatment and control.

Problem statement:

Leprosy remains one of Brazil's far-reaching public health crisis. Although worldwide rates of the disease significantly dropped between 2000 and 2006, Brazil still has a long way to go before leprosy is no longer considered a public health issue. The prevalence in Brazil was 1.27 per 10,000 inhabitants in 2014. This is in comparison to the global prevalence 0.29/10,000 according to WHO during 2016. This is a stark difference from the majority of Latin America and the Caribbean that has eliminated the disease as a public health issue. This persistence in Brazil was likely a result of a combination of factors that ultimately diminished the quality of healthcare patients of Hansen's disease received.

The population of Brazil is extremely diverse. The world's second largest population of Black people (first being Nigeria) live in Brazil. More specifically, of the total 11.2 million, taken from Central and Western African during the North Atlantic Slave trade, Brazil received close to 5 million, more than 40% of the slave population, notes African-diaspora expert, Henry Gates Jr (Pollack, 2011). Societal understandings of racial identity very from community to community, this is demonstrated in the Brazilian ideology of racial democracy. Anthropologist Gilberto Freyre introduced an idea known as racial democracy in his work *Casa Grande e Senzala* (Freyre, 1946). It was in this work he explains that racial democracy was a phenomenon of Brazilian society that supposedly made it different than racism in the U.S (Freye, 1946).

Despite this, the legacy of slavery and colonialism have huge impacts on health outcomes, education, etc. for people of color in Brazil. In such a population, race-driven inequalities and injustices are common, especially in healthcare where a patient's skin color can drive negative attitudes and perceptions from a healthcare provider. These types of racial prejudices can have a serious and impactful effect on the type of care a patient receives as well as heavily influence patient's experiences within the healthcare system. This issue of racial prejudice is further compounded in Brazilian society given the history of forced separation and extreme stigmatization of against leprosy patients present in Brazilian society. Additionally, a lack of financial and educational resources can hugely increase the vulnerability of an individual with leprosy. These factors contribute to creating a system where patients suffering from leprosy do not receive adequate assistance and are continually neglected.

This qualitative project, aims to better understand the effects of perceived racism, socioeconomic status and stigma and how these factors affect experiences of leprosy patients of Minas Gerais, Brazil. In doing so, aspects of the Brazilian healthcare system will be identified that can be improved to better serve and aide these patients. These findings, including the lived experiences of patients, can also be used to develop more equitable health care programs that address stigmatizing diseases and help patients of color from low-socioeconomic and disadvantaged communities.

Purpose statement:

This study will better improve understandings of Brazilian patients' experiences with leprosy as well as additionally identify factors that could be targeted to improve their health, treatment, and accesses within the healthcare system. More specifically, this project will improve understandings of how perceived racism, socioeconomic status and stigma affect patients experiences with the disease as well as expand knowledge and understandings on their journey within the Brazilian healthcare system. Additional insight will be given in regards to how patients access care as well as make health-related decisions. This study of perceived racism and the role of socioeconomics on the lives of patients in Brazil and how it relates to a stigmatized disease will be particularly fruitful, given the country's large, multi-racial population, complex race and social relations, and considerable social and economic diversity.

Research question:

Research question: How do differences in race, socioeconomic and perceived stigma influence experiences of leprosy patients of Brazil?

Hypothesis: Low income, highly stigmatized non-white Brazilian patients express worsened experiences when compared to their white counterparts.

Significance statement:

As rates of leprosy continue to rise in the developing world, attention must be placed on the role that race, socioeconomic status, and perceived stigmatization play on one's experience. The ability to identify short fallings and challenges in the experiences of people affected by leprosy will give great insights to clinicians, policy makers, and public health officials as to where and how improvements can be made.

Definition of terms:

Favela- a Brazilian low-income, informally constructed neighborhood

Branco/a- White-skinned.

Moreno/a- Tan-skin or olive-skinned, usually dark haired.

Pardo/a- Brown-skinned.

Negro/a- Black. Deep brown-skinned.

Aposentado- Retired.

Chapter 2 Literature Review

Introduction

The ways in which social determinants impact physical, emotional, and social health has been a topic of interest within the research sphere for many years. Race is often explored as a factor that affects both individual and population health and can be defined as "an arbitrary classification of modern humans, sometimes, especially formerly, based on any or a combination of various physical characteristics" (Merriam Webster's Collegiate Dictionary, 2019). The American Anthropological Association notes that race is a historical and socially constructed concept, and that "the human populations are not unambiguous, clearly demarcated, biologically distinct groups" and that "present-day inequalities between so-called 'racial' groups are not consequences of their biological inheritance but products of historical and contemporary social, economic, educational, and political circumstances (American Anthropological Association, 1998). Through various studies explored in this text, race has been identified as a factor that influences health, as the majority of research finds that racial minority groups face significant social, economic, and political barriers to accessing health resources when compared with the racial majority group (Myers, 2008).

Stigma, another social determinant of health, within the global health context can be defined as a "social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group" (Sillo, 2016). Stigma is an incredibly impactful facet of the leprosy experience, and it can manifest itself in several forms: experienced stigma (Sillo et al., 2016), perceived stigma (Borges-De Oliveira et al., 2015), and self-stigma (Sillo et al., 2016). There is a large body of literature on leprosy and the Brazilian context specifically, though very little focuses on how racial identity affects patient experience. These studies largely utilized quantitative methods such as patient and physician interviews, with some employing surveys as measures of the impact of stigma on a patient's life. The studies focused on leprosy stigma in Brazil were chosen in order to represent the diverse methodologies utilized within the topic, with relatively large sample sizes being taken into account as well.

There is a clear relationship between health and socioeconomic status. Generally, individuals of a lower socioeconomic status face health risks at a much higher rate than individuals with a higher socioeconomic status. Leprosy is an example of a treatable disease, yet it is still prevalent in many nations and mainly affects those in the poorest regions. Brazil has the highest rates of leprosy in the Americas. Case studies, (examples explored below) have shown the correlation between low socioeconomic status and higher leprosy rates in Brazil. This literature review examine articles exploring the relationship between socioeconomic status and health in general, the socioeconomic disparities in health behaviors, and then how socioeconomic factors have contributed to leprosy rates in Northeast Brazil. The review will then examine the evidence presented in the article, identify what still needs to be researched, and the practical implications that can be learned from them.

Race

Racism and Health Disparities: An Overview:

In recent years, the relationship between perceived racism and health outcomes has been increasingly explored, with a variety of literature and data being produced and analyzed persistently (Myers, 2008). Racism and discrimination have long been recognized as interpersonal and systemic experiences that contribute to the unequal power structures and societal systems existent today. However, the concept that racism influences population physical and mental health directly is a more contemporary research pursuit (Myers, 2008). Much of the existing literature today regarding this topic focuses on how self-reported experiences of perceived racism and discrimination impact the physical and mental health outcomes of those affected, and how these outcomes can be analyzed and correlated accurately.

In an analysis done in 2008, “Race, Racism, and Health: Disparities, Mechanisms, and Interventions”, by Myers et. al., the study attempted to bring together a variety of literature regarding the relationship between health and experiences of racism and outline the reasons that this association has been made (Myers, 2008). Myers explains the negative health outcomes that racial and ethnic minorities face through research completed in regards to the social, political, and economic disadvantages many minorities face, and how these experiences play into their ability to maintain healthy lifestyles (Myers, 2008). Myers cites that racism is a significant psychological stressor that allows for an inhibited ability among many populations to adequately partake and be included in society and limits these populations’ capacity to gain economic opportunities (Myers, 2008). In short, this analysis expands on the effects systemic and interpersonal racism has on populations as well as individuals in terms of their access to resources (i.e., adequate clinical care, proper medical care, a supportive social network) and how this inhibition, in turn, perpetuates poor health outcomes, in terms of psychological stress, low socio-economic status which prevents communities of Color from obtaining medical information and assistance, and many other necessary resources for achieving well-being (Myers, 2008). This analysis of the overview of the association of perceived racism and poor health outcomes provides background on the further, more in-depth literature to follow. Although this subject of research has become increasingly prevalent in recent years, there is still a need for further empirical and quantitative data regarding the direct and indirect effects of racism.

The most prevalent literature in regards to physical health implications when faced with persistent structural or interpersonal racism determines that cardiovascular disease, respiratory problems, and hypertension are the most common physical conditions that can result from experiences of racism. In terms of mental health, unrelenting and chronic high stress levels, anxiety, and PTSD are all cited as common psychological health outcomes in regards to experiencing racism (Lucas, 2016). Although this literature is quite comprehensive, several limitations exist within aspects of each study. All of the data determined in studies above regarding experiences of racism are self-reported and, because of this, much of this data can be limiting due to its reliance on individual, subjective accounts. Additionally, many studies used scales, this study enlisted the Racism and Life Experiences scale, which can often be interpreted differently and results can be inconclusive (Lucas, 2016). Regardless, the literature and data expressed by the study explored above are critical analyses on how the impacts of systemic and interpersonal racism reaches beyond the social sphere, and has biological implications as well.

Race and its Effects on Leprosy in Brazil:

Despite available data studying experiences of racism and discrimination can have on population and individual physical and mental health, there is a lack of literature regarding this phenomenon in terms of the experiences of those with leprosy in Brazil. There is a collection of research (subsequently reviewed) that speaks on the stigma experienced by leprosy patients in Brazil, however, racism and discrimination's role in levels of leprosy prevalence and access to treatment is not explored extensively (Borges-De Oliveira et. Al., 2015) (Garbin et al., 2015)

(White, 2007). However, a study completed by Dr. Cassandra White in 2007 focused on the stigma that leprosy patients, throughout the world, experience stigma through encounters with physicians, society, or biomedicine in general (White, 2007). White's research involves ethnographic research conducted in Rio de Janeiro, Brazil, which focused on participant observation and extensive interviews among people who work or visit the outpatient treatment centers within this area for leprosy (White, 2007). Although White's main intention was to explore the stigma that patients of leprosy within these outpatient treatment centers, she also examined the effects of the medication needed to treat leprosy, and how the side effects of the medication impacted the stigma that many patients reportedly faced (White, 2007). Through interviews with both men and women who live with leprosy in Rio de Janeiro, participants expressed extreme distress regarding the darkening of skin color due to the medication required to treat leprosy, MDT drug clofazimine (White, 2007). Many patients reported unwanted comments from members of their communities due to the darkening of their skin, and many others, within White's study perceived this side effect to be the impetus to exposure to discrimination (White, 2007). White recounts that, in many patients that she interviewed, many expressed disdain as they began to be perceived as black or darker in skin tone, and experienced racism and discrimination because of this (White, 2007). Importantly, White's study explores the racial hierarchy present in Brazil, and the barriers that leprosy patients have to face to get treated for the disease (White, 2007). However, this study is also qualitative, and relies on a large amount of self-reported data, which is a potential limitation (White, 2007). Although White's study touches upon the racial implications and discrimination leprosy patients risk facing, further research on this topic is needed, as there is significant evidence that racism plays an essential role in predicting poor health outcomes and could contribute to the persistence of leprosy in Brazil.

Socioeconomic Effects on Leprosy in Brazil:

The Northeast region of Brazil suffers from the highest rates of leprosy, with 33.5% of newly diagnosed cases in Brazil coming from that region (Kerr-Pontes, 2006). It is also the poorest region, with a GDP/capita of approximately $5,119 (Northeast Region, 2009). Additionally it is a region of the country with the largest black population. The industrialized southern region of Brazil, with cities such as Sao Paulo and Rio de Janeiro have a GDP/capita almost double the north-east region at $10,000 (Northeast Region, 2009). An article in the International Journal of Epidemiology titled "Socioeconomic, environmental, and behavioral risk factors in Northeast Brazil" aimed to identify the components associated with leprosy rates in this region. The study took place in the State of Ceará, located in the northeast part of Brazil. This region has an illiteracy rate of 28% in citizens over the age of 15 and is one of the poorest states in the country (Kerr-Pontes, 2006). The population was studied through patients diagnosed with leprosy over the previous 2 years through the Ceará Ministry of Health and study cases were selected from outpatient clinics (Kerr-Pontes, 2006). Over 200 people with leprosy were studied and another 800 were used as controls (Kerr-Pontes, 2006). The study was broken up into blocks based on the demographics of the patient. Block 1 was based on socioeconomics and was based on schooling, experience of food shortage, access to safe drinking water, and sewage/type of floor in home. The findings of the study showed that those with low schooling made up 58% of the cases studied, those with a middle level of schooling made up 25%, and those with a high level of schooling made up only 18% of patients with leprosy (Kerr-Pontes, 2006). Five out of the eight variables in the behavioral block were associated with increased risk of leprosy. These included low frequency of changing bed linen, hunting 10 years previously, hunting armadillo, fishing, and weekly regular baths in open bodies of water (Kerr-Pontes, 2006). Those who reported experiencing food shortages had rates of leprosy 1.54 times as high as those who did not (Kerr-Pontes, 2006). Changing bed linens and weekly baths in open water relates to water shortages and the lack of access to clean water that many poor Brazilians face in their day to day lives (Kerr-Pontes, 2006). Those with not enough to eat are not getting the proper nutrients needed, resulting in weakened immune systems and possibly are more susceptible to leprosy. The implications from this study were that low education levels, water shortages, and food insecurity at any point in life are significant socioeconomic risk factors for leprosy (Kerr-Pontes, 2006).

Stigma and its Effects on Leprosy in Brazil:

Stigma is deeply negatively impactful for patients with leprosy in Brazil. The three types of stigma, experienced stigma (Sillo et al., 2016), perceived stigma (Borges-De Oliveira et al., 2015), and self-stigma (Sillo et al., 2016), have significant impacts on quality of life, and the majority of leprosy patients who report suffering from stigma experience an interlacing of two or three types. Experienced stigma often manifests itself in the family or workplace. Family members will perform prejudiced actions such as refusing to eat from the same plates or sleep on the same bed, which can greatly impact a patient's self-esteem and well-being (Sillo et al., 2016). Some patients report discrimination in the workplace or outright discriminatory dismissal from work due to a disclosed leprosy diagnosis (Garbin et al., 2015). Perceived stigma has significant effects on the mental health of leprosy patients, with those reporting high rates of perceived stigma often demonstrating a lower quality of life and perceptions of worse health outcomes (Borges-De Oliveira et al., 2015). Self-stigma is usually a two-fold process. First, cultural perceptions of leprosy derived from very stigmatizing accounts from the Bible produce a lot of public stigma that leprosy patients internalize (White, 2007). This is often exacerbated by difficult experiences that patients face because of the illness, such as disability or unemployment, leading them to develop low self-esteem and eventually, self-stigma (Sillo et al., 2016). These varying sources of stigma largely work together and influence the lives of leprosy patients in negative ways.

It is crucial to note that low socioeconomic status, in comparison to those patients with higher socioeconomic status, is directly linked to more severe stigma experiences and impact. Those who obtain a delayed diagnosis of leprosy tend to be from a lower socioeconomic status, with this delayed diagnosis leading to more severe manifestations of leprosy symptoms, including physical deformities or even disability (Garbin et al., 2015). These physical markers of leprosy worsen the levels of stigma experienced by patients in various life dimensions such as interpersonal relationships and in the workplace (Garbin et al., 2015). Additionally, those in lower socioeconomic strata have more difficulty accessing quality care or care in general, which can lead to debilitating health consequences (White, 2007). Seeking care for leprosy reactions after MDT is also a barrier for those with financial difficulties, and without proper care during these episodes, severe symptoms will likely manifest (White, 2007). Race is another important factor to take into account when discussing stigma. In Brazil, race and socioeconomic status are inextricably linked (Bucciferro, 2017). As such, the links between socioeconomic status and greater impact of stigma on quality of life can likely be applied to race as well, with Black Brazilians experiencing more severe instances of stigma. There is racist subtext even in the manifestation of stigma for those who experience skin darkening and discoloration as a result of treatment. Some patients describe experience a change in "racial categorization" due to this skin darkening, and therefore facing instances of prejudice from those close to them, in the workplace, or among strangers (White, 2007). It appears that the more deeply interlaced stigma, socioeconomic status, and racism is for a patient, the more difficult their leprosy experience will become.

According to a 2016 study on the temporal and sociocultural exploration of the stigma experiences by leprosy patients of Brazil, though stigmatizing attitudes of leprosy in Brazil are less severe than in the past, low-income Brazilians continue reporting accounts of discrimination and shame. Leprosy patients experience discrimination by the government, their family members, and in the workplace. Although the Brazilian government has abolished mandatory isolation, lingering effects of the practice still leave many misconceptions of the disease. Upon diagnosis, a patient's family members are often times afraid of contracting the disease and avoid contact with the patient. In the workplace, leprosy patients have been historically forced to leave their positions once diagnoses are disclosed (Sillo et al., 2016). Furthermore, a 2018 report on social determinants, their relationship with leprosy risk and temporal trends in a tri-border region in Latin America, found that an individual's income and race are direct determinants linked to the risk of infection (Simionato de Assis et al., 2018). Specifically, in Brazil, these statistics were found to come about through the consequences of social inequality (Simionato de Assis et al., 2018). Historically in the country, people of brown race/color have lacked access to an education. Without proper education, people are unable to work in higher-wage jobs and lack opportunities to live in homes with proper sanitation. In this instance, leprosy risk may be associated with access to safe water and sanitation (Simionato de Assis et al., 2018).

First, the "labeling" of patients as having leprosy vs. Hansen's disease was an important theme in various interviews and observations (White, 2007). While it is rare that the highly stigmatized word *lepra* "leprosy" be used in medical contexts nowadays in Brazil, the label of "Hansen's disease” (*hanseniase)* is beginning to carry stigma in itself (White, 2007). There were some patients who expressed a suspicion of the term “Hansen’s disease” because they felt it was misleading or used by physicians to shield them from the truth of their illness (White, 2007). Additionally, the similarity between the Portuguese word for cancer (*câncer*) and the abbreviation for Hansen’s disease (*Hansen*) was another source of fear expressed in interviews (White, 2007). The researcher recommends that in the initial explanations and conversations around a leprosy diagnosis, physicians should use the word leprosy to an extent and emphasize the connection between the two names (White, 2007). This can empower the patient with knowledge of their condition and give them more resources to discuss it with other people (White, 2007).

The second form of identifiable iatrogenic stigma came from “biomedical procedures”: skin smears and biopsies (White, 2007). Skin smears generally leave patients with some kind of bandage on one of their earlobes, which can become a “marker” for leprosy to the public, or at the very least a marker of a serious health issue (White, 2007). Biopsies create even more severe marks, often leaving scars in certain body parts that can seriously impact a patient’s self-esteem (White, 2007). Many patients expressed that they greatly disliked the painful “holes” that were created from these procedures (White, 2007). A social worker who was interviewed believed that there was excessive use of these invasive techniques, and that this can sometimes lead to patients not returning for treatment at the clinic (White, 2007). It appears that physicians may need to more carefully and consistently evaluate the benefits and detriments of certain procedures before implementing them.

Another significant facet of iatrogenic stigma is that of leprosy and disability. One physician who was interviewed believed that while many people hold the false belief that leprosy causes disability, this is only true if there is a severe lapse in medical care and delay in treatment (White, 2007). This is an important point, because while leprosy-related disabilities or deformities should no longer occur, they do and bring about stigma and lower quality of life (White, 2007). One of the largest, if not the largest reason behind the development of disabilities is the large numbers of misdiagnoses that occur prior to reaching the leprosy diagnosis and being able to receive treatment (White, 2007). In this sample, 40% of participants reported having received the wrong diagnosis before discovering it was leprosy (White, 2007). This delay in disease detection is derived from many sources, such as lack of leprosy specific training, misconceptions about early symptoms, or insufficient diagnostic tools (White, 2007).

A miscommunication that can also lead to serious disability is the idea that leprosy is cured after the full MDT treatment. While this is technically true, “leprosy reactions”, or leftover immune system complications, can cause “progressive nerve damage” if left untreated (White, 2007). Physicians must understand a patient’s circumstances when explaining the possibility of leprosy reactions and how to prevent serious consequences through follow-up care (White, 2007). To continue spreading the idea that leprosy is totally curable without fully explaining leprosy reactions, while possibly reducing stigma, it can create life-threatening circumstances for patients and should be reevaluated (White, 2007).

The location of treatment can also be a source of iatrogenic stigma. There has been a great effort to decentralize leprosy care and make it accessible in any health care clinic, however this has not spread throughout the entire country (White, 2007). There are 33 clinics or treatment centers that reside in former leprosariums, and one of the clinics in this study represents this group. Six of the eight educational meetings on leprosy took place in this treatment center, and it was clear that staff needed to address the history of the clinic and assure patients that they were safe and well-cared for there, without facing additional stigma (White, 2007). An additional important consideration is that with leprosy treatment options being spread to general clinics, those being treated for leprosy may experience more stigma in these settings than other patients (White, 2007).

Clearly, there are a variety of dimensions in the medical domain that can bring about or perpetuate stigma experiences for patients with leprosy. While this is not meant to indict health care professionals, it is important that they understand these facets and work towards improving patient experiences and addressing the gaps (White, 2007). Oftentimes, iatrogenic stigma is closely linked to stigma experienced outside of the medical domain, which places responsibility on health care teams to identify and alleviate these experiences (White, 2007).

Experienced, Perceived, and Self-Stigma:

In 2015, a "cross-sectional, descriptive study" was conducted to understand the profile of leprosy patients and the types of stigma experienced by them (Garbin et al., 2015). This was achieved through the administration of surveys to 94 participants who were patients in the Reference Center in Cuiaba, Mato Grosso, Brazil. Of the 94 patients, 55.3% were male, and all patients were between 24 to 82 years old, with the highest number of participants being in the 40-49 years bracket (Garbin et al., 2015). A large number of participants had lower levels of education, with 62 participants not having completed high school and only one participant having completed college (Garbin et al., 2015). Approximately, 41.5% of participant were employed, and 67% earned one to three times the minimum age.

The questionnaire was divided into three sections: 1) demographic information, overview of participant living conditions and illness, 2) participant knowledge of leprosy, treatment, public perceptions, and shifts in their lives as a result of illness, and 3) existence of "leprosy episodes" or reactions, and the effects of leprosy on quality of life of the participant (Garbin et al., 2015). Bivariate analyses with chi-square tests were conducted as the primary form of analysis of survey responses (Garbin et al., 2015).

There were several pieces of the first section of the survey that were worth noting. First, 51% of participants discovered their illness when a family member or person close to them suggested they see a professional, however 58.5% of participants were hesitant to seek care (Garbin et al., 2015). The primary reason for this hesitation was not viewing it as important (56.4%). All participants were receiving multidrug therapy (MDT), with 66% citing their reason for adhering to treatment as wanting to be cured (Garbin et al., 2015) . The largest difficulty participants had with treatment was the side effects from medications (44.7%) (Garbin et al., 2015). There were 25 (26.6%) participants who presented with leprosy reactions (Garbin et al., 2015). Additionally, 72.3% of participants know someone else who has leprosy (Garbin et al., 2015).

In the second part of the questionnaire examining participant knowledge and attitudes towards leprosy, 60.6% expressed that they did not feel people generally know about leprosy (Garbin et al., 2015).When asked what they knew about leprosy before their diagnosis, 52.1% understood that it was contagious. Interestingly, all participants were aware that once MDT began, the disease was no longer "contagious" (Garbin et al., 2015). A majority of participants (55.3%) believed they contracted the illness through contact with a relative who had leprosy (Garbin et al., 2015). When asked about prejudice against those who have leprosy, 93.6% of participants believed that prejudice occurs (Garbin et al., 2015).The central fear of a large number of participants (39.4%) upon diagnosis was physical disability, followed by fear of rejection (25.1%) (Garbin et al., 2015). Notably, 92.6% of participants reported fearing long-term complications, or sequelae, of the illness (Garbin et al., 2015).

The third and final section revealed that 45.7% of participants rated their quality of life as either bad or very bad, with 25.6% rating it as "not bad but not good"(Garbin et al., 2015) . In relation to experiencing debilitating pain, 39.4% of participants described it as "a lot", and "36.2%" experiencing it to a lesser but still present extent (Garbin et al., 2015). In life satisfaction, 62.8% of participants described themselves as dissatisfied, and 58.5% of participants reported having negative feelings often to very often (Garbin et al., 2015). Participants also rated their satisfaction with their ability to work, with 46.8% of people describing themselves as dissatisfied to very dissatisfied, and 24.5% being ambivalent (Garbin et al., 2015). Researchers found statistically significant links between leprosy episodes and lower quality of life ($p < 0.001$).

In terms of stigma, 52.1% of participants were fearful of informing their family about their diagnosis, a fear that largely came from fear of rejection (63.3%) (Garbin et al., 2015). Additionally, 95.7% of participants reported other people being afraid of approaching or being near them once they had knowledge of the illness (Garbin et al., 2015). Despite these difficulties, 96.8% of participants related having supporting families (Garbin et al., 2015). Many patients experienced various issues at work (69.1%). These issues ranged from experiencing stigma in the workplace (50.8%), to being forced to take a leave (24.6%), or to being fired (12.3%) (Garbin et al., 2015). Researchers also found significant links between a participant's self-evaluation of their ability to work and issues in employment ($p = 0.001$).

These quantitative results have some important implications in regards to stigma. First, it is crucial to note that participants generally came from a lower socioeconomic status, leading to a higher risk of more severe and debilitating aspects of the disease (Garbin et al., 2015). Additionally, many participants reported great difficulty in dealing with treatment side effects, particularly because they often manifested as physical changes that often lead to prejudice (Garbin et al., 2015). These difficulties, as well as troubles at work and shifts in self-perception lead to a lot of negative emotions and lower quality of life in participants (Garbin et al., 2015). Participants also expressed a great deal of fear of experiencing stigma, which would also lead to masking their illness (Garbin et al., 2015).

There are several recommendations in this study that could alleviate the difficult experiences of many leprosy patients. Many patients had a lack of understanding on leprosy and many misconceptions before receiving their diagnosis, and they felt this was true of the general public as well (Garbin et al., 2015). To disseminate more information on leprosy through various media platforms could be immensely beneficial (Garbin et al., 2015). Participants revealed that their diagnoses were much delayed, partly because they did not believe they had a serious illness, but also because medical professionals failed to detect it (Garbin et al., 2015). Improvements must be made in detection and diagnosis in order to prevent worsening conditions. In practical terms, a “multidisciplinary team of health professionals”, including “health system managers”, would need to be built to improve the education of the broader public as well as assist in the reintegration of leprosy patients back into society (Garbin et al., 2015).

These quantitative methods established some clear patterns of stigma experienced by leprosy patients. Those in a lower socioeconomic status often have delayed diagnoses and more severe symptoms (Garbin et al., 2015). Treatment often brings many physical side effects which result in greater experiences of stigma, which creates a cycle of negative emotions and interpersonal and well as professional issues (Garbin et al., 2015).

Perceived Stigma:

In 2015, Borges-De Oliveira et al. conducted a study to understand whether there are significant differences on the impact leprosy has on quality of life of patients depending on the presence of neuropathy and perceived social exclusion (PSE). The study originally recruited 160 participants from two leprosy reference centers in Salvador, Bahia, Brazil. Due to missing data in medical records, 34 patients were excluded (*N* = 126). Participant ages ranged from 18 to 79 years (*M* = 42.1, *SD* = 15.5), and 56.3% were male (Borges-De Oliveira et al., 2015). There was a relatively even breakdown between married (46%) and single (45.2%) participants, with 8.7% being divorced or widowed (Borges-De Oliveira et al., 2015). In terms of employment, 62.7% of participants were employed, while 21.4% had lost their jobs because of leprosy (Borges-De Oliveira et al., 2015). The rest of the participant pool had been unemployed or retired before their diagnosis. All patients were receiving MDT, and 84 participants had the multibacillary variation of the illness (Borges-De Oliveira et al., 2015).

Data was collected through clinical interviews going over several surveys. Questionnaires obtaining demographic and perceived social exclusion information were distributed. The MINI PLUS (*Mini International Neuropsychiatric Interview Brazilian Version*) was administered to diagnose psychological disorders (Borges-De Oliveira et al., 2015). Quality of life was measured through the SF-36, a health survey exploring eight domains: “physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health” (Borges-De Oliveira et al., 2015). Medical records were also utilized in order to understand neuropathy or lack thereof in patients (Borges-De Oliveira et al., 2015). The researchers also posed the question “Do you feel excluded or discriminated by other people?” to participants, with options ranging from “unbearably” to “no” on a Likert scale (Borges-De Oliveira et al., 2015). In order to understand the consequences of neuropathy, stigma (PSE), and their combined effects on quality of life, participants were divided into four groups: control, or those who did not have neuropathy or PSE (41.2%), "perceived stigma", those with PSE but no neuropathy (17.4%), neuropathy, those with neuropathy but no PSE (17.4%), and "stigma neuropathy", those with both PSE and neuropathy (20.6%) (Borges-De Oliveira et al., 2015).

The MINI PLUS psychiatric survey revealed that 59.5% of participants met the criteria for an anxiety disorder, and 40.4% exhibited depression symptoms (Borges-De Oliveira et al., 2015). Quality of life for those in the "perceived stigma" ($p = 0.04$) and "neuropathy" ($p = 0.05$) groups was demonstrably lower than those in the control group in the "general health" domain (Borges-De Oliveira et al., 2015). Those in the "neuropathy" group also reported lower quality of life in the "role-physical" dimension ($p = 0.02$) (Borges-De Oliveira et al., 2015). Those in the joint "stigma neuropathy" group had significantly lower quality life scores compared to the control in the following spheres: "role-physical" ($p = 0.02$), "general health" ($p = 0.02$), "social functioning" ($p = 0.04$), and "role-emotional" ($p = 0.04$) (Borges-De Oliveira et al., 2015).

These results demonstrate that neuropathy and perceived stigma are common among leprosy patients (57.9% of participants reporting at least one of these), and when these two dimensions of the illness come together, quality of life seems to be even more severely affected in patients (Borges-De Oliveira et al., 2015). Quality of life seems to be particularly impacted by physical limitations and difficulties, declines in health, stunted social functioning, and emotional difficulties (Borges-De Oliveira et al., 2015). This implies that while medical treatment for neuropathy is very important for leprosy patients, psychological care for those experiencing stigma is also crucial (Borges-De Oliveira et al., 2015). It is important to note, however, that a causal relationship cannot be gleaned from the "cross-sectional design" of the study, and that the sample size is limited, particularly with the conditions being broken down (Borges-De Oliveira et al., 2015). The researchers recommend an "integrative care approach" to be taken so that the complex dimensions in patient's lives that are impacted by leprosy can be fully treated (Borges-De Oliveira et al., 2015). They also believe that resilience in leprosy patients should be studied, especially in the context of neuropathy and perceived stigma (Borges-De Oliveira et al., 2015).

The familiar theme of stigma and physical disabilities or deformities is strongly present in this study, highlighting the need for holistic care addressing mental health impacts of stigma and physical symptoms that patients must cope with.

Conclusion:

Race, as explored by the literature outlined in this review, has been determined to be a significant factor in impacting poor health outcomes for many populations across the world. Research on the relationship between race and health has shown that belonging to a racial minority group disadvantages many individuals and populations from a health standpoint, as many people of color do not have access to adequate health resources and practices. The most prevalent literature in regards to physical health implications when faced with persistent structural or interpersonal racism determines that cardiovascular disease, respiratory problems, and hypertension are the most common physical conditions that can result from experiences of racism, along with a plethora of other physical health ailments and diseases. In terms of mental health, chronically high levels of stress, anxiety, and PTSD are all cited as common psychological health outcomes in regards to experiencing racism, which allow for poor health outcomes in terms of psychological health. Although this literature is quite comprehensive, several limitations exist within parts of each study. All of the data determined in studies above regarding experiences of racism are self-reported and, because of this, much of this data can be limiting due to its reliance on individual, subjective accounts. Additionally, the majority of studies used scales, like the Racism and Life Experiences scale, which can often be interpreted differently and results can be inconclusive. Regardless, the literature and data expressed by these studies are critical analyses on how the impacts of systemic and interpersonal racism reaches beyond the social sphere, and has biological implications as well. All these factors suggest that race may be a factor in poor health outcomes in those with leprosy or at risk for leprosy.

The status of health of a population varies considerably, even within the same country. Several studies have shown the correlation between socioeconomics and health. Generally, individuals of a lower socioeconomic status face health risks at a much higher rate than individuals with a higher socioeconomic status. A lower socioeconomic status leads to a lower quality of health care received and low-income individuals have little or no extra money to spend on expensive medical treatments. For example, leprosy is a treatable disease, yet many all around the world suffer from its devastating effects. Brazil is the country with second the highest burden of leprosy in the world. Case studies have found that socioeconomics are a major factor in the risk for contracting leprosy. The northeast of Brazil is one of the poorest regions, with 58% of the country making less than $2 a day, in the country and also accounts for over a third of leprosy rates (Garmany, 2011). Those with low income, little access to clean drinking water, and high illiteracy rates were more likely to have leprosy than those who had a higher socioeconomic status. Likewise, behaviors such as hunting and bathing in open water, that are more frequently engaged in by poor individuals, had positive correlations with increased risk for leprosy.

Those in a low socioeconomic position tend to have higher rates of unemployment and financial loss, which can lead to engagement in unhealthy behaviors such as smoking, that account for the differing mortality rates between high income and low-income individuals.

Health promotion work undertaken by government workers in disadvantaged areas is a key role in allowing the public to make positive lifestyle choices to improve health in the future. Likewise countries such as Brazil must develop policies that tackle the risk factors associated with contagious diseases such as leprosy.

The literature on stigma and leprosy in Brazil is a bit more extensive than that on socioeconomic status and racism specifically, with several notable studies being conducted with stigma as the primary focus. These studies have revealed that stigma is derived from negative cultural perceptions surrounding leprosy, as well as physical symptoms of leprosy that arise from lack of proper and timely care, such as deformities or disabilities that can interfere with patient functioning. In order to combat stigma, researchers recommend that public awareness campaigns become more widespread, and that large-scale training on early leprosy diagnosis be administered to doctors across the country. While there is certainly more of a focus on stigma faced by leprosy patients in Brazil than on other facets of the leprosy experience such as socioeconomic status and racism, there is certainly more to be studied in the topic. One such area are the ways in which socioeconomic status, racism, and stigma work concurrently in impacting patients with leprosy. The present study aims to explore these links, highlighting areas that have not been previously studied in-depth.

Methodology:

Introduction:

For this study, twelve qualitative interviews were conducted and three oral histories were taken from adults affected by leprosy in the Minas Gerais state. All interviews were conducted between the sites of Eduardo de Menezes Hospital and Santa Isabel leprosarium.

Population and sample:

This project was be based in the cities of Belo Horizonte and Betim, in the state of Minas Gerais, Brazil. The area has a high annual incidence of leprosy at 34.3 cases/ 100,000 (DeCastro, 2016). More specifically, all interviews and oral histories were taken at the former leprosarium, Colonia Santa Isabel and Eduardo de Menezes Hospital (a regional infectious diseases hospital that houses the state-wide leprosy). Included in the study were six adult leprosy patients with leprosy that present to the dermatologic clinic. Additionally the study included six adult residents of the Santa Isabel community.

The study was exclusively conducted in these two sites. Participation in the survey was completely voluntary and respondents could choose not to respond to any questions that they did not wish to. Additionally, participants could stop the interview at any point. A verbal consent was conducted prior to every interview. All participants' names were changed to maintain confidentiality.

Research design:

The study recruited twelve participants affected by leprosy of diverse racial and socioeconomic backgrounds. These individuals were either newly diagnosed, on multi-drug therapy or completed multi-drug therapy. Additionally, the study aimed to recruit participants from diverse locations around the region but this ultimately was not a priority in the field. In the end, a 20-question questionnaire was used with topics ranging from racial identity, to clinical access, to perceived discrimination in clinical settings.

Procedures:

In both the clinic and at Santa Isabel a flyer around the clinic and hospital in an effort to recruit patients to participate and provide their expertise insights during long wait times. Additionally, medical staff, students, and administrators served as gatekeepers to additionally recruit potential participants. Lastly, a snowballing technique was employed to encourage participants to share their experiences and recruit their friends, though no participants were ultimately recruited through this means. In the field, we worked to conduct all qualitative interviews, as well as oral histories, with all participants. Prior to all interviews a verbal consent took place which ensured all participants were explained the project, their rights as a participant, as well as their ability to stop the interview at any time. The interview guide was ultimately 20 questions long and oral histories were open ended allowing participants to share what parts of their story they found most relevant to the research topic. All interviews and oral histories were recorded on a password-safe phone. Hard copies of all consent forms were stored in locked cabinets at Faculdade de Saúde e Ecologia Humana. Upon returning to Emory, all data were stored on private servers, only accessible with a unique username and password. All identifiable information was de-identified in transcripts as well and also stored on password protected computers.

Plans for data analysis:

All interviews and oral histories were transcribed, uploaded and analyzed using MAXQDA for qualitative analysis. Firstly, codes were identified to begin to note patterns within the data. Following the identification of initial codes, memos were applied in an attempt to identify broader concepts and issues within the data. A code book, and subsequent definitions, were developed and used in the analysis of all data, stopping only when saturation was met. Once the codebook was completed, it was used throughout out all interviews to begin to identify greater trends and patterns. In-vivo coding was useful as a lot of similar words and phrases were repeated by multiple participants. Results were ultimately quantified in a graphic. Ultimately, a narrative analysis approached was used to analysis data. The case-based approach allowed for analysis of entire interviews. Structure, content, and core of narratives were analyzed.

Ethical considerations:

This project was approved by the Institutional Review Board of Emory University in the United States (IRB00087575 and IRB00104864) and by the Ethics Research Committee of the Faculdade de Saúde e Ecologia Humana in Brazil.

Results:

Introduction*:*

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Overall, only eleven interviews and the three oral histories were analyzed using MAXQDA, with one excluded from analysis due to inaudibility. All names and identifiable characteristics featured in the findings have been changed to protect patient anonymity.

	Alessandra	Daniela	Eduardo	Francisco	João	Jose Luis	Julia	Roberto	Ronaldo	Thais	Maria Luiza	Results
Racial Identity	morena	branca	pardo	bracno	pardo	pardo	parda	pardo	negro	negra	negra	9.1 %morena, 18.2% branc@, 27.3% negr@, 45.4 %pard@
Treatment location	outpatient	outpatient	colony	colony	outpatient	colony	outpatient	outpatient	colony	colony	colony	45.5% treated as outpatient, 54.5% treated within colony
perceived race affected treatment	no	yes	yes	no	yes	no	no	no	yes	yes	yes	45.5% treated as outpatient, 54.5% treated within colony
expressed idea of racial democracy	yes	yes	no	yes	no	no	yes	yes	yes	no	yes	36.4% no, 63.6% yes
perceived socioeconomics affected treatment	yes	no	yes	yes	no	no	yes	yes	yes	yes	yes	27.3% no, 72.7%yes
perceived education affected treatment	no	no	no	yes	no	no	yes	no	yes	yes	yes	45.5% yes, 54.5% no
perceived stigma affected treatment	yes	yes	yes	yes	no	yes	yes	yes	yes	yes	yes	9.1 %no, 90.9 %yes
identified social support affecting treatment	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	0% no, 100% yes

figure 1

Findings*:*

Race Data:

Analysis focused initially on individual perceptions of racial identity. Of the eleven participants, one identified as *moreno/a* (tanned skin) (9.1%), two identified as *branco/a* (white skinned) (18.2%), three identified as *negro/a* (black) (27.3%), five identified as *pardo/a* (brown-skinned) (45.5%). 2010 national data shows national distributions of the aforementioned racial categories as 7.61% *preto/a*, 43.13% *pardo/as*, 47.73% *branco/a*. National data does not list moreno/a as a racial identity option on the survey (Brondolo, 2012).

When first asked about perceived racial discrimination, all respondents stated that they have never experienced racism, or other discrimination based on their racial identity. When probed further on whether racial identity impacted treatment in healthcare, all participants revealed experiences of racial discrimination. Additionally, the absence of perception of differential treatment based on racial identity does not mean that it doesn't have an impact on health; it might just be evidence of internalization of the racial democracy myth.

Alessandra, a middle aged, financially independent, *morena* small business owner initially described a picturesque Brazil in which there was absolutely no racism. The daughter of a father who she said was *negro* and a mother who she said was *branca,* she describes racial relations within the healthcare system as "great, really great." Expanding to explain that all, regardless of race, are, "extremely well received, you know." When probed with situational examples of racism in the healthcare system and beyond within greater Brazil, she was initially unable to identify any examples. This was an experience also shared by Roberto (who identified as *pardo),* who expressed no differential treatment against leprosy patients across racial lines.

The results highlight a contrast in experiences of those treated within the colony and those treated as outpatients. While those at the colony all similarly initially expressed race having no bearing on experience, all participants expressed a specific distinction between life within the colony and life beyond. Francisco (80-year-old, *branco*) expanded on this idea often. He did not state having knowledge of racial differences beyond the colony but was very intentional on sharing his understanding that life beyond the colony was much different from that of life within. Of the seven participants interviewed in the colony, all but one unpromptedly expressed sentiments of the colony serving as its own mini society, blocked and isolated from greater Brazil. There was a general understanding that societal norms and customs of the colony, were not those beyond her gates in greater Brazil. Francisco's neighbor, Thais, 75-year-old *negra* expressed and expanded on this sentiment of major racial relations and differences beyond colony walls. She states:

> "Ah, outside the colony was different, eh? ...I was very afraid of discrimination, of being discriminated against, so I never liked leave the colony to buy things...I was very afraid to leave so discriminated out there."

Fellow colony resident José Luís echoed these sentiments; always distinguishing between here (in the colony) and there (life beyond the gates.) He, like the majority of his fellow colony community members, described a vastly distinct society, as well as general social norms within the colony and beyond. Ronaldo describes the colony as "our own little city." Data highlights that this differential understanding of less perceived racism within the colony can be explained by a sense of one's identity as a "colony member" being all-encompassing, leaving little association with other secondary identities, such as race. Due to the physical isolation from greater Brazil, this individualist mindset began to flourish and became common amongst community members.

When initially speaking on racial identity in Brazil, Daniela appeared to be almost confused, before quickly stating, "I think we are all one common race. Because, Brazil, our country, is made of mix races Dutch, Japanese, Italian, ne. So, I consider myself a normal person." She expresses a common idea that the "normal" Brazilian is a mix of many different backgrounds, resulting in one common Brazilian, with no possibility of discrimination or differential treatment at the hands of race. Similar to Daniela, Julia, Alessandra, João, Ronaldo, and Roberto expressed similar ideas of a "racial communality" across Brazil that, they explained, would make differential treatment at the hands of race incomprehensible. However, the case proves to be more complicated.

As previously mentioned, while all participants initially said that they thought race had no influence on their healthcare experiences with leprosy, all but one participant eventually shared examples of race negatively affecting either their experience within the clinical system or beyond. Maria Luiza explains, “Whites always have more ... possibility. It seems that black people were meant to be slaves. And the whites were made to be in command. Not everyone accepts this ideology. I am one of them.” Fellow colony resident Ronaldo similarly expressed preferential treatment of whites in the colony. He shared that prejudice and what he perceived as racial discrimination in colony classrooms were common. Ronaldo explained: “There are always white people, lighter skinned people. They are more, more called, and sometimes they are not so smart, right.” An important distinction was made here as well. Ronaldo highlights that race, especially race in Brazil, is extremely nuanced and transcends far beyond ideas of blackness and whiteness. Skin tone is an incredibly important factor as well, and colorism is still a significant factor in race relations in Brazil. He highlights that while the white population was small, preferential treatment was also shifted to those of lighter skin tones.

Despite this idea of heightened “racial democracy” understood to be true within the colony, Thais shared a discriminatory experience in which she accidentally overheard colony clinicians speaking to one another. She shared,

> “"Funny that [the nurse] works here inside the colony hospital... but she's kind of new, started working now, and she's a nurse... So [the nurses] started to talk about discrimination, and one of the [nurses] in our group said to me, "well, I keep looking because from time to time I see discrimination here [within the colony], discrimination against blacks, discrimination against leprosy patients, discriminating against the poor ”… They have to discriminate yes.

Following this anecdote, Thais did not identify having ever experienced racism, despite the nurse's admission of discriminating against colony residents. This is important contrast as she recognized the statements as racist and the recognition of these women working in the colony as potential problematic. Still, she did not identify racial discrimination as an issue within the colony or a problem she experienced personally. Systematic racism, or racism occurring at a societal level, was not expressed by any participants besides Thais.

Surprisingly, as participants began to identify ways in which race results in differential treatment of leprosy patients, four participants expressed concerns of race affecting clinician ability to perform accurate diagnostics. Julia, João, José Luís, and Daniela expressed concerns of clinicians' ability to identify skin stains on deeper skin tones. Julia was of the many participants who initially shared race having no bearing on clinical treatment. A few moments after her initial response, she went on to state her perception of the potential negative outcome of having deeper skin tone in clinical leprosy setting. Julia stated, "Look, with my skin tone at least, I think makes a difference, skin tone, eh. Now, I think it would be much harder to find [skin lesions], right. For example, my mom's black [very deep skin tone], right. So, I think, due to her skin tone, and by the pigment [of the lesion] being lighter, I do not know, I think sometimes it would be more difficult to identify, right?"

Fellow outpatient João expressed similar sentiments; initially expressing race had played no effect on his treatment in the health system. Like Julia, following further thought he expressed concern of clinician ability to diagnose deeper, darker skin tones have a much harder time seeing and identifying lesions. He states, "If it were darker it would be harder to see the spots, ne. If it were whiter it would be easier to spot the spots".

Socioeconomic Data:

Similar to perception of differential treatment due to race, major experiential differences were noted between data retrieved within the colony and data retrieved in the outpatient clinic. All but one participant from the colony received treatment prior to the inclusion of leprosy medication in the Sitema Unico de Saúde (SUS), coverage, meaning all treatment, medication, and clinical visits required out of pocket fees. The idea of a financial burden and associated expenses were pervasive and commonly stressed among colony participants.

Francisco heavily elaborated on his inability to support himself during his years of treatment. He explained there were often times that there were not enough funds to support basic needs. He explained, “most of the time essential were the time. Most of the time the essentials are missing. I really, really felt it because at the time the state gave nothing. Not even a "good morning, good afternoon, ** laughing ** good evening”... In the past, no, nothing.” Despite the laughing, these memories of financial insecurity, and an inability to support himself were extremely troubling for Francisco and he found himself crying on and off throughout the interview, ultimately resulting in a series of short breaks throughout. This experience of extreme financial struggle, and an inability to support clinical needs, was shared by many of the colony residents. Thais expands stating her former financial burdens as “a very great suffering. We used to be very worried because we did not have an income.” With little opportunity for economic growth once in the colony due to a lack of work opportunities, the large majority of residents, who arrived without any financial funds, found themselves struggling to support not only the large economic burden of disease, but subsequent, basic living expenses. For some, this financial burden had effects on treatment plans. Due to high medical costs associated with leprosy in the past, Daniela shared that there were often periods of time in which she ultimately went without clinical care due to an inability to pay- a reality of many seeking treatment at the time. The longest she ever had to go without accessing proper care was three months due to an inability to pay.

All but one of colony participant was treated prior the introduction of SUS he was also the only colony participant to not express financial burden and fear in association to his diagnosis. This was similarly expressed with the remainder of outpatients who never experienced out of pocket medical costs for medications (all began treatment after 2000). Forty-three year old outpatient, Roberto, expressed a recognition as well as an association with his class and his success conquering the disease many years prior during treatment. At one point, while explaining his prior commitment to his treatment that, “when I was in treatment … I moved nearby so it made it much easier” he recognized the benefit of being closer to his treatment and as well as the associated ease in going back and forth. He recognized this move was due to his financial security as well as job title. He additionally shared that like Julia, due to his work, he feels a certain level of financial liberty. When asked about fiscal decision making, Roberto noted that in the past it was common for those with his similar diagnosis to have to make difficult decisions around spending. He described a family in which there was little money and there was a need to choose between buying dinner and paying for medication. He expanded on the complexity of this decision as well as the dire replications either choice could cause a leprosy patient. A decision, with presence of SUS, he states many Brazilian families no longer have to make, though some do. He hypothesized that it was highly possible, part of the large, poor majority, there was likelihood patients are left to choose between treatment and basic necessities. He shares, “between buying dinner and coming to the hospital, there are a lot of people who will buy dinner".

Outpatient João does not associate his low socioeconomic level with any differential treatment. He expressed sentiments of not having enough money to get everything he desires and needs, but did not attribute this with his diagnosis. Additionally, he didn't have any association of differential treatment with his socioeconomic status. But, he did express the burden of costs to commute to the clinic. While there are closer clinics, his preferred provider only works in this specific clinic. This was not an issue for João as he expressed a deep understanding of the importance of his monthly clinic visit. Additionally, he noted a wait of 45 minutes due to his inability to access private clinicians and visiting private services. He felt this has had no effect on his employment opportunities, and that his employer is aware of his diagnosis and need to go to clinic one a month. Long commute times and associated costs were an idea shared by Ronaldo as well whose 1.5 hour commute includes two transfers, each requiring additional out of pocket payments.

Across both communities, amongst participants, those of higher socioeconomic level have a higher association with positive perceived experience with leprosy than those of a low socioeconomic level. This can be most clearly understood in the analysis of the experiences of Julia, Roberto, and Maria Luiza. Successful small business owner, Julia, describes her economic status as “autonomous” and of “steady, consistent income.” She expressed due to her owning of the business, there is a large level of flexibility in her schedule. She goes on to expand that she owns her own car with which she travels an average of fifteen minutes to arrive to the clinic. Roberto, who similarly expressed fiscal comfort, expressed that he never misses any appointments, as he has identified consistency as key to treatment. When asked what he would do if the bus to get to the clinic was not running he replied I’d find "access to car, motorcycle, Uber today, right.” When questioned on high cost of Uber in Brazil he responded, “yeah, it does require a [higher] cost but were speaking of one’s health it's worth it." While there was understanding of the potentiality for high cost, his financial security ensured that this potential increase in the cost of accessing necessary care was never a concern or cause of worry. Maria Luiza similarly identified as someone of higher socioeconomic standing. Interesting to note, upon arrival to the colony, Maria Luiza met with her father who was already a resident of the colony. Her father was *aposentado*, meaning he was of retired standing and was receiving sums of his own money from the colony. This created a constant flow of income for Maria Luiza, her sister who she arrived with, and their father. She noted this created a sense of security and comfort she herself did not recognize in many of her neighbors. She recognized that this stability and comfort was almost unheard of during that era in the colony.

Data examining the effects of socioeconomic status within this study did not solely focus on income and ability to support oneself, but also encompasses education levels. Data showed that the majority of participants identified a way in which their education level influenced their experience with leprosy, or leprosy affected their ability to pursue education. Findings suggests that higher level of education in participants was associated with higher sentiments of empowerment and self-efficacy. Julia identified that her heightened education provided a lot of aid. Identifying benefits of education for patients as, “a big help to understanding the disease” and “helpful in searching for information, with this I think it helps a lot.” More specifically, she concludes, “The less educated the person, the more this weighs one down.”

Maria Luiza, a proud self-identified autodidact, expressed very similar views of the beneficial role education has on patients. Maria Luiza explained her mother’s constant recognition of the power of education and its ability to aid with potential social mobility. She recounts her mother saying to her “I did not want illiterate children, I do not want illiterate children ... I want them to study, I want children who learn, who can the future, help me." An idea, Maria Luiza explained, her mother continually insured her daughters understood, even once residents of the colony. While not given the chance to pursue formal upper education, Maria Luiza read all she could during her formative years, learning any chance she could. She ultimately worked for 34 years before retiring. Eight of these years teaching and the remainder as a healthcare professional in the colony.

As previously mentioned, despite obvious intelligence, discrimination barred Maria Luiza from pursuing her highly desired education. She expressed gratitude for the education she received in the colony, but also the additional unfulfilled dream of education beyond the colony. A dream always hindered by her leprosy diagnosis. She shared,

> "After the colony opened up [schools outside the colony] still didn't accept, to receive the kids from here to enroll there .... I liked [the colony school] but wanted to continue my education, but I could not. It was my dream, I had the will, schooling was not challenging to me ...But I could not go any further with my studies ... The diagnosis got in the way of the study… I wanted to study more and I could not …"

Expanding, she shares a feeling of entrapment from her diagnosis. This idea of one's diagnosis hindering education pursuits was additionally shared by Francisco. In describing his formative education and previous school prior to his arrival at the colony he shared that his schooling experience within the colony was worse like worse than that in the favelas. Through tears, he highlighted the educational pursuits of his brother, now a lawyer, and shared his jealousy of never receiving the same opportunities.

Lastly, and of equal interest, increased education, was additionally expressed by many participants as one of the core reasons for improved lived experiences. Participants identified that as knowledge and general understandings leprosy increased, levels of discrimination began to subside.

Stigma Data:

Stigma was found to have a substantial role in the lived experience of leprosy patients. Interestingly, many participants associated stigma with a lack of education. For example, Roberto states it “[prejudice because of leprosy] hurts then when the people sometimes pass judgment it was likely due to a lack of knowledge. Because if I do not know one thing I tend to say, "what's that"? I think it would not even be a prejudice, it would be a lack of knowledge. I will give an example, a dog with lesions in the body * inaudible * you do not discriminate, you just will not get close if you do not know what is wrong with him. You know? It would be a fact of the person not to know the disease.” Specifically, data highlights recognition of a lack of understanding or knowledge as common perception amongst participants. Participants explained in the past, especially high levels of stigma and discrimination could be noted within the health care center, namely from clinicians. In one of Roberto’s earliest memories with clinicians, he remembers receiving treatment with a barrier wall placed between himself and the clinician due to high fear levels around the spreading of disease. Patients were not free to leave the colony and very few who weren’t mandated to, wanted to enter beyond its gates. He explains simply, “they were scared.” Alessandra echoed this sentiment stating, “when I did not know ... when the population doesn’t know the disease yet, I felt a bit of prejudice with regard to being “the one with leprosy” or “the leper”. But today after everyone knows, it's being treated like a common disease and it has a cure, you know?”

Stigmatization due to leprosy was noted by all participants. When asked if she ever felt stigmatized because of her diagnosis, Julia says no, but later expands stating, “not in my case, because I never share my diagnosis *laughs* I know people have prejudices about everything. With color, disease, social class, because of this I'd rather not talk... When someone asked me "what is it?"[lesion] I say, "Oh, this is a sunspot." Her understanding of prejudice and fear of possible stigmatization has stopped her from sharing her diagnosis with anyone besides per parents. When asked by customers about her skin marks, she describes them as “skin spots.”

Another participant explained, when asked if he had ever fallen victim to feelings of stigmatization due to his leprosy diagnosis she shared, “Yes, yes. And they went a thousand times. Oftentimes. Even with my family. Everything, you see?” He, like many other participants highlight that stigmatization of participants has potentiality to occur by one’s own family. Stigmatization and discrimination from one's own family was a concept rich in the data. Numerous participants expressed that they were never visited by their family or they received word that certain members of the family had cut ties following diagnosis. Daniela highlights, “the stigmatization I felt was from my own family, you know, like I said my own family.” Upon her arrival, she lost word from her father’s family and has not received word back since her initial arrival in 1957.

Of last note, the role of stigma can be seen in the vast and extensive vernacular on the topic of interest. Six participants expressed experiencing stigmatization in the form of name calling. For example, words such as *negra* and *lepra*, were found to be especially stigmatizing. Commonly used terms used by participants to describe these terms were “heavy” and “words that bite.” Ronaldo, in tears, shares his reaction following a verbal assault which resulted in a bus attendant refusing a sale due to his leprosy diagnosis. He explains, “Yes, people hurt [me] a lot [with their words.] Hurt, you know. We-we-we *soft crying* are left without st-st-st-strength for anything.” This experience had lasting effects as following it, Ronaldo refuses to leave the colony for thirteen year due to fear of stigmatization and discrimination.

<u>Discussion:</u>

Introduction:

The results of this study give great insight into perceived experiences of people affected by leprosy in the healthcare system. A focus on race, socioeconomics, and stigma allowed researchers to take a novel approach to understanding the role that social factors play in the overall patient experience. Data generated from this qualitative analysis provided great insight on patient perspectives of the effects of race, socioeconomic status and perceived stigma on their experience as a leprosy patient. The data proved to be enlightening on how different identities and lived experience shape patients' health and perception of disease, beyond biology. While individually, race, socioeconomics and stigma were found to influence experiences with leprosy, results of these data suggest that race, socioeconomic status, and stigma all work coherently, rather than in a siloed manner, to influence lived experiences of patients.

Race:

A majority of studies focusing on effects of race or perceived racism on health outcomes heavily focus on American communities. While Brazilian data is available, an increased focus on the impact of race, especially how it interacts with socioeconomics and stigma, on the disease could serve useful. The results do so with American understandings of racial history, definitions of race, and cultural and communal understandings of race (Kaholokula, 2016). The dispersion of racial identities among participants suggests that rates of leprosy are higher in non-white participants than white participants when compared to racial dispersion at the national level (Ligia, 2006). It is imperative that leprosy-focused research expands to examine the relationship between racial identity, perceived racism, and patient experiences.

As previously mentioned, almost all participants expressed that racial discrimination in Brazil was nonexistent due to the vastly diverse "melting-pot" nature of the country. The racial democracy was incredibly persuasive in the data. As expressed by Freyre, due to Brazil's extensive racial diversity, there is subsequently no discrimination in the country as everyone, to a certain extent has similar racial background (Freyre, 1946). This is an intrinsically Brazilian ideal and results express that this idea is deeply imperative to understanding the impacts of race and racial identity in Brazil. This idea of racial democracy appeared throughout the data, creating unexpected nuance. Ideals of racial democracy were especially prevalent within the colony. Beyond this, there was a large concern among patients that clinicians were not able to confidently diagnose disease and identify the disease amongst non-white communities, especially among the darkest of the population.

Beyond racial identity, participant results also highlighted the influence of racial identity on their experience with the disease; more specifically, if experiences of non-whites were varied at the hands of race. When speaking about race in interviews, the most extensive data were collected with the use of anecdotal probes. In conclusion, data around perceptions of the effects of racial identity differed greatly based on geographical location. The biggest distinction can be noted between those treated as outpatients and those interviewed within the colony. Participants from the colony expressed sentiments of isolation and removal from the greater Brazilian society due to their diagnoses. Many suggest this isolation resulted in a further promotion of and deeper identification with the idea of racial equity

In terms of perceived racism, this was not expressed as a concern for participants. Rather, numerous participants identified and expressed concern of clinical abilities in identifying disease and treating it on deep skin tone. Of those who did express experiences of perceived racism, most cited fear, or experience, that occur within clinical settings. Further research with deeper understandings of Brazilian race relations is necessary to expand understandings of the impacts of racial identity and perceived racism on leprosy experiences.

Socioeconomics and Stigma:

Diverse experiences were noted amongst those treated as outpatients and those treated within the colony. Overall, those treated as outpatients expressed that socioeconomics had little to no bearing on their experience with leprosy, a drastic difference from experiences of those treated in the colony. A lack of income, and more importantly, an inability to pay for treatment and medication affected the experiences of participants of the colony. This is not caused by the location in which care was received, but rather the era in which care was received. With the introduction of SUS, an extreme the socioeconomic burden formerly associated with the disease quickly was addressed as the program covered treatment costs for all Brazilian.

All but one colony resident noted that socioeconomic instability served as a big point of stress. Expanding that often a lack of money, paired with an inability to gain employment left many unsure of how they could afford treatments. While there is not extensive data on the topic, these findings do support literature findings with heavy burdens of disease and worse patient experiences associated with lower socioeconomic status. Additionally, many patients noted that while SUS lowered cost associated with the disease, the quality of care provided was not standardized and very much varied across regions. Many attributed their high commute times to wanting to receive the high quality treatment at the particular SUS clinic interviews took place. This could ultimately create additional burden and for those who cannot make the economic commitment to this journey.

Literature explains there are three types of stigma often associated with leprosy experiences: experienced, perceived, and self-stigma (Sillo, 2016). All three types were experienced amongst participants. As previously mentioned, stigma was found to have significant influence on patient experience, a finding that matches literature cited. Additionally, as previously mentioned, low socioeconomic status, or economic instability intersected with experiences of high levels stigma had pejorative infection on participant experiences (Gornick, 2002). This literature finding was matched by experiences expressed amongst participants. While not expressed nominally as “experienced, perceived, or self-stigma,” the ideas expressed by these phenomena are expressed amongst participant responses.

Literature specifies that late diagnosis is associated with low socioeconomic status and manifests in more intensified symptoms, including deformities and even disability (Garbin et al., 2015) (White, 2007). This was heavily expressed amongst participants of the colony and the opposing sentiment can additionally be understood amongst outpatient participants. Colony residents expressed that due to low socioeconomic status, many were often left with very visible, physical manifestations of their disease, making their disease status easily visibly identifiable. This experience was also supported by literary findings which explains that these now physical markers of leprosy worsen levels of income and stigma as it often heavily affects interpersonal relationships as well as in the workplace (Garbin et al., 2015). The benefits of early treatment and diagnosis can be noted amongst participant responses. Because of early detection and treatment, there was no expression of a stigmatization due a physical manifestation caused by an inability to access treatment for fiscal reasons. This development amongst participants is important as it shows progression in treatment. Again, the introduction of SUS allowed for these care-associated costs to be assumed by the government, and not individual patients.

Literature notes additionally that those of low socioeconomic status had harder time accessing quality care, both literature and participants explain (Financial Conditions and Health Care Burdens of People in Deep Poverty, 2015) (Gornick, 2002). So, while SUS has increased access to care, literature and participants have identified the need for increased access to quality care.

Lastly, an increased education, for both laymen and clinicians could serve as incredibly useful in addressing these issues around stigma. Education around the disease, its high prevalence in the country, treatment options as well as warning signs should be included in this education. Both literature and participant responses note that education of themselves and an increased education around the disease were identified as necessary to address stigma (Institute of Medicine, 2002). Strong social support was also found to counteract stigma and low self-esteem education.

Unexpected Findings:

There were certain data that yielded unexpected results. The first of the aforementioned findings that was unexpected was the role of racial democracy in the formation of Brazilian racial identity. Additionally, the continuous mentioning of the SUS health system, its benefits, and positive aspects was unexpected. More specifically, results were rich in data from all participants explaining the benefit of the SUS system as well as the praise of leprosy being covered by the system. The introduction of SUS was a key factor when examining differences amongst participants and the biggest variation across participant experiences occur in those treated before the introduction of SUS and those treated after. One can note that a majority of participants from the colony had similar understands and outpatients had similar outlooks, as the majority of both parties received treatment in the same era. In the end, when gaining insight on patient experience, a focus on socioeconomic status and perceived stigma were found to be more influential on one's experience than race.

Beyond differences in treatment, patients of the colony expressed that due to the colony's isolation, societal rules beyond colony walls were different from those of the colony. Maria Luiza explains, "We had a band and then we had a very good ensemble, you know. Jazz ensemble. We had lots of good things. I really miss this time. In time when we had things just for us? Our things. Because it was our little town. It was our environment, our little town, made up of all ours. Our musicians, our singers, our patients, our employees were all ours." This idea of community and social support was imperative to positive patient experience, both in the colony and beyond. Examples of this beneficial social support were noted by all participants. Julia explained that her family members always travel to the clinic with her and are active in her treatment. Roberto highlights that his boss and coworkers know of his diagnosis and are not only understanding, but supportive of his treatment. Finally, Francisco notes his move to the colony to be closer to family as pivotal to his successful treatment. He emphasizes his need to be closer to family and loved ones during what he described as "the hardest period of his life."

Racial discrimination within the colony, though an issue, was not identified by any participant. While outpatients had many layering identities, data suggests that participants of the colony identify as leprosy patients and other identities such as race, and socioeconomics are less attached to one's sense of self. Two participants also shared that discrimination of religion had been an issue within the colony. Participants shared that historically, the Catholic majority were highly favored as the colony was run by Catholic nuns and clergy. The non-Catholic minority, such as Ronaldo, expressed differential treatment because of this. Treatment he says he suffers to this day. Today, this differential treatment can still be noted in the cemetery that is segregated into a Catholic and non-Catholic section.

In the end, perceived differential racial treatment was not as significant of a determining factor as expected. Potentially this can be attributed partly to the idea of racial democracy felt around the nation. Additional factors such as social support, education, and socioeconomic level were found to have much bigger bearing on the lived experiences of leprosy patients than race. A strong sense of racial identity, as well as a sense of being educated and capable of learning, served as sources of empowerment for participants.

Limitations

While few, there were weaknesses in this project that could be considered limitations. The first of these limitations is the small number of study sites featured in the study. While saturation was met amongst study participants, the addition of more study sites in which to recruit participants could yield additional results that could better represent the Minas Gerais state. An additional limitation to this study could be the only involvement of just twelve participants. While this is a good sample size given the qualitative nature of the study, given the large prevalence of cases across the entire nation, a larger sample size from multiple communities could generate more detailed and rich data. Saturation (no additional sampling would yield to more findings) was met in the results, but a larger sample size could ensure that optimal socioeconomic and racial diversity was present in the participant population. Another significant limitation of this project can be seen in language skills. While Portuguese language skills of the team were very strong, researchers were not native speakers of the language nor native of Brazil. A major strength of this project was the inclusion of Brazilian leprosy experts from the planning of the interview guide to the analysis process to ensure cultural competency and appropriate approaches to the sensitive topic.

Implications:

Leprosy is thought to be first introduced in Brazil in the sixteenth century (ILA, 2019) and since then, the disease has become endemic throughout the country. Social factors, as well as history, have large effects on health outcomes. In the context of leprosy, additional focus and continued research on these sociocultural factors, with special focus on stigma, could begin to lessen the burden of disease felt from the individual to federal level in Brazil. With acceptance of these more diverse research approaches, one could potentially expect for Brazil to have a more substantial decrease in both leprosy prevalence and incidence rates.

Three recommendations have been identified as key for future researchers. Firstly, as previously mentioned, heightened value needs to be placed on patient experiences (i.e. continuation of qualitative research in the form of interviews, focus groups, and surveys) to allow patient experiences to shape clinical understandings of endemic diseases. A focus on qualitative research can help explain some of the sociocultural culture nuance of diseases. It is additionally recommended that leprosy education is increased at all levels (community, clinical, federal etc.). This education will allow community members to have accurate information about the disease, its prevalence in the region, and treatment options. Similar information can be made available for clinicians of the country. It can serve as especially useful for those in endemic regions to have supplemented educations that include not only the history of leprosy, but also special considerations to be taken when treating these patients (i.e. Hansen's is more appropriate and less stigmatizing than Leprosy.) Lastly, increased intersectional funding and collaboration (ex. clinicians, politicians, anthropologist, sociologists, and economists) is needed to create a task force whose intersectional focus is centered on the sociocultural implications that play on the lives of patients.

Conclusion*:*

Racial identity was expected to have a much more profound effect on perceived patient experience, but this was not the case. Across all participants, social class and leprosy-related stigma had much more impactful effects on patient experiences. The experiences expressed by patients reflects literature findings and thus further research must be done in the context of Brazil to further these understandings and control continually rising leprosy rates. Brazil has the second highest rate of leprosy worldwide, and incidence continues to rise. It is important to continue to conduct qualitative research to further highlight patient experience with leprosy, as their opinions and experiences could continue to shape the outcomes of care, education, and policy transformations. It is imperative to continue to address stigma around the disease, as this social factor has strong pejorative effects on patient experience and treatment.

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