Distribution Agreement

Alexandra Llovet April 15, 2019

Stigma Continuity of Leprosy in Brazil, 1924-2018

by

Alexandra Llovet

Dr. Ana Teixeira
Advisor

Spanish and Portuguese

Dr. Ana Teixeira
Advisor

Dr. Jeffrey Lesser
Committee Member

Dr. Xochiquetzal Marsilli-Vargas
Committee Member

2019

Stigma Continuity of Leprosy in Brazil, 1924-2018

By

Alexandra Llovet

Dr. Ana Teixeira
Adviser

An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts with Honors

Spanish and Portuguese

2019

Abstract

Stigma Continuity of Leprosy in Brazil, 1924-2018

By Alexandra Llovet

Leprosy exemplifies the social, physical, and mental repercussions that disease can have for patients. Brazil and India have the most newly diagnosed cases of leprosy per year. From the 1920s to the 1970s, Brazil's health policies required that patients be placed in leprosaria distant from their loved ones and isolated. These policies traumatized and dehumanized patients. I use an interdisciplinary approach to analyze the continuity of discrimination and stereotyping of leprosy in Brazil. This project aims to spread awareness that leprosy is still a problem to be addressed and develop an understanding of the power and longevity of disease stigma and stereotypes. Over two summers in Brazil, I compiled four types of sources from 1924 to 2018: (1) literary sources, (2) visual sources, (3) medical records, and (4) oral narratives. Using literary analysis of themes and representations, I analyze visual and literary sources of Leprosy in Brazil. I gathered ten oral narratives of healthcare workers and patients through snowball sampling in two leprosaria, a state reference hospital, and local clinics. I used medical records (1920s-1980s) from the Emilio Ribas Public Health Museum's archives in São Paulo that show a narrative of the patient's lives in the leprosaria, detailing runaways, removed children, etc. and clinical treatment. The pool of sources helps understand life when labelled a "leper" in Brazil. Through the diversity of sources across time and intended fields (literature, art, public health), I show the continuity of stigma and fear despite leprosy's curability since 1941. I analyze the diverse origins of the stigma of leprosy and suggest that the cultural phenomena surrounding leprosy has a longstanding impact on patient's quality of life. Leprosy in Brazil shows the failure of purely biomedical medicine in treating patients. Lack of empathy and consideration for patients' quality

of life has longstanding effects that persist even after a biological cure is discovered. Public health campaigns should target the many origins of leprosy stigma to help fully mitigate patient discrimination.

Stigma Continuity of Leprosy in Brazil, 1924-2018

By

Alexandra Llovet

Dr. Ana Teixeira
Adviser

A thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts Honors

Spanish and Portuguese

2019

Acknowledgements

First and foremost, I would like to thank Dr. Jeffrey Lesser for always having faith that I would be able to accomplish my goals (even when I doubted myself). For two years, Dr. Lesser pushed me to produce better work, and I am forever grateful that he saw in me what I could not see in myself.

I would also like to thank Dr. Ana Catarina Teixeira for helping me understand my own thoughts and unpack what exactly I am trying to communicate. Dr. Teixeira taught me Portuguese and read every page of this thesis too many times for the sake of making me a better researcher. This project would not be nearly as convincing if it wasn’t for her consistent effort to provide useful feedback. Thank you, Dr. Teixeira, for your time and dedication.

A big thanks to Dr. Xochiquetzal Marsilli-Vargas for helping me understand essential theories for my project. Thank you for being a part of my thesis committee and providing feedback throughout this journey.

I had several peers make my experience in Brazil exceptional. Thank you, Doris Cikopana, Jennifer Choe, Julia Lee, and Daniella Gonzalez, for all the memories. Each one of you has a dear place in my heart, and I am excited to see everything each of you accomplishes. I am sure there are amazing things in all of your futures.

Thanks to Fernando Cosentino, Juliana Casagrande, Delphine Lacroix for welcoming me with open arms in Brazil and sitting through countless, long-winded discussions about my project. You helped me visit several archives that housed key evidence for my thesis. Another big thank you to the Museu de Saúde Púbilca Emilio Ribas, particularly dedicated archivist Maria Assad, for helping find many of my archival sources.

Thank you, Dr. Jessica Fairley, for allowing me to tag along in Belo Horizonte. You and the employees at the Eduardo de Souza Lima helped me gather several of my narratives and understand how leprosy is treated today.

I would like to thank the Emory community for encouraging me to pursue an ambitious, multidisciplinary project. Thank you to the College of Arts and Sciences, the Fox Center for Humanistic Inquiry, and the Halle Institute for Global Research for funding my research project and providing feedback as I went along. A big thanks to Dr. Uriel Kitron that also helped me obtain funding as a sophomore when the project was really just an interesting, far-fetched idea. This project would not have been possible without the Spanish and Portuguese Department. Rosana Philips and Dr. Katherine Ostrom helped me learn Portuguese in class and outside of class, and for that reason, I was able to effectively communicate in Brazil.

Most importantly, I would like to thank my parents and grandmother for supporting every single one of my crazy adventures. Your unrelenting support means the world to me.

Table of Contents

Introduction

In 2017, I arrived in Brazil with a proposal to research artistic representations of a disease. I was unsure of what disease or what particular themes to analyze. My advisor, Dr. Jeffrey Lesser, a historian at Emory University, suggested that I and fellow health researchers meet with the team of archivists at the Emilio Ribas Museum of Public Health. The small museum located in the Bom Retiro neighborhood specifically focuses on the history of diseases in Brazil and houses extensive archives of disease related documents. While at the meeting, an archivist mentioned leprosy as a potential disease that would fit my interests of social aspects of disease. I began preliminary research on its transmission, treatment, and Brazilian public policy.

In Brazil, isolation of leprosy patients continued for thirty-two years after doctors began to prescribe a cure for patients. This fact drove me to explore the representations of leprosy in Brazil across different mediums. I gathered four types of sources, from the beginning of isolation in 1924 to the end of my ethnographic work in 2018: visual sources, literary sources, medical records, and oral narratives. Since beliefs about diseases can come from many sources (including art, literature, television, patients, clinicians, and the government), the sources together show a more complete depiction of people's perceptions of leprosy from 1924 to 2018. The sources represent the cultural phenomena surrounding leprosy which often affects patients negatively through stigma and discrimination.

A diagnosis of leprosy carries for the patient heavy biblical connotations of sin, disfigurement, and contagion. Since 1941, leprosy has been curable through antibiotic treatment. Furthermore, less than 5 percent of the population is susceptible to the bacterium. Nonetheless, many people still believe leprosy patients are condemned with a crippling, deadly disease and that leprosy spreads rapidly and ruthlessly. These misconceptions have continued the stigma of leprosy for centuries. Even in 2018, I met patients that struggled with the social consequences of leprosy. While physicians and public health campaigns acknowledged that leprosy patients should not be isolated, the general public continues to socially isolate patients and even physically isolate patients at times.

As I looked through my diverse pool of sources that ranged over a century, I expected to find differing perspectives on leprosy, but I was surprised by the many similarities in the discourses in art, literature, medical records, and oral narratives. The theme of stigma consistently came up whether I was talking to patients diagnosed in 2018 or looking at a painting from the early twentieth century. I chose to analyze the continuity of stigma to highlight the absence of change in the patient experience despite the changes in medication, legislation, and politics in Brazil. Each source provides a unique take on the experience of leprosy patients with stigma and/or help explain the many sources of the stigma since 1924.

Methodology

One of my challenges as a leprosy researcher was finding sources on a disease society purposely tried to hide. Initially, I expected to focus my project on leprosy representations within one field (art, public health, literature). I figured I would gather as many portrayals of leprosy as I could and decide which medium I would specifically analyze later. In trying to overcome the challenge of finding sources, I established a unique, interdisciplinary pool of sources that reflected the many origins of stigma for leprosy. I use oral histories to document patient experiences with stigma and leprosy. These histories provide post-isolation (1976-2018) perspectives on leprosy, detailing the ongoing stigma despite the cure to leprosy and the 1976 outlawing of isolation in leprosaria. Occasionally, these histories also provide first-hand experiences to back my analysis of visual and literary sources. The visual and literary sources provide evidence of the cultural phenomena surrounding leprosy throughout isolation (1923-1976) and post-isolation. I occasionally use accounts from medical records to support my analysis of stigma with patient experiences from the isolationist period. The four types of sources (visual source, literary sources, medical records, and oral narratives) combine to provide a unique analysis centered on the continuity of the theme of stigma in different mediums and time-periods. This analysis highlights the many sources of stigma that need to be targeted by public health campaigns, incorporates patient experiences and consequences of stigma on health, and maintains an emphasis of the influence of the arts on public discourses of disease.

First, the visual sources consist of paintings, Department of the Prophylaxis of Leprosy of Sao Paulo's photographs of both leprosaria and patients, and public health publications for disease prevention. I analyze how the disease is represented in these pieces and what it means for the overall discourse of the disease at the time. These sources portray the visible symptoms of the disease and public health campaigns to support isolation. This gives me the opportunity to address the physicality of the disease as well as different perspectives on isolation. Visual representations of leprosy are particularly important because most leprosy patients in Brazil are illiterate. Therefore, it is probable that their own perceptions and their family's perceptions of the disease stem from visual representations. These representations contribute to the discourse surrounding leprosy in at risk communities and reflect cultural perceptions of leprosy in Brazil throughout the century.

Second, I analyze the descriptions of leprosy in the literary sources, including poems and short stories. The poems and short stories directly mention or reference leprosy. I occasionally analyze references to leprosy in novels to support my arguments. Novels reference the disease on limited occasions. I do not analyze the entire novel but limit myself to the moments where the words “leprosy” or “leper” appear. I searched the novels for those specific words and read the chapters in which they appeared. Literary sources allow me to analyze the internal discourse of narrators and patients. This provides a discussion on what physical aspects authors specifically emphasized and the emotions of patients and/or nonpatients related to leprosy in literature. The visual and literary sources are evidence of the discourse in which people participated at the time. I dissect the themes that continuously appeared throughout both to understand the culture surrounding the disease in Brazil.

Third, I read through medical records of leprosy patients from the state of São Paulo from the 1920s to the 1980s. The Emilio Ribas Museum of Public Health houses thousands of these medical records. With my limited time, I asked the archivist to choose one box of medical records from each decade for me. I read through the first ten files of each box for a total of 70 medical records. The medical records demonstrate the state’s heavy monitoring of patients, by documenting the physiological health, marriages, escapes from the leprosaria, and visitation requests of patients. I used these extensive files to detail the experiences of patients in leprosaria during the isolation period. As I looked through the files, I took note of records that reflected the stigma faced by patients and the impact isolation had on leprosy stigma. I use this evidence as indirect narratives of patients’ lives in isolation.

I gathered oral histories from patients and healthcare employees. In order to find these participants, I contacted healthcare workers in two health clinics. I did two home visits with public healthcare community agents to meet patients. After those two visits, I struggled to find patients and healthcare workers treating the disease. At a loss, I consistently shared my project with archivists, professors, and healthcare employees with the hopes of some direction. I met with Dr. Roney Cytrynowicz, a Brazilian historian in São Paulo and one of Dr. Lesser’s friends, with the hopes that he would recall any literary representation of leprosy or an archive that would be useful to me. Dr. Cytrynowicz became interested in my project. He offered to drive me to a leprosarium, Pirapitingui, a couple of hours from São Paulo. He said our conversation had left him curious and wondering what a leprosarium looked like. I spent one day in a leprosarium, Pirapitingui, where I saw the structure of isolation firsthand and met several patients that still live there. Similarly, I met with Dr. Jessica Fairley, an epidemiologist and physician at Emory University focusing on leprosy research, for advice on my leprosy research project. She mentioned that she would be traveling to Belo Horizonte, Minas Gerais to continue her work and gave me the opportunity to join her. With Dr. Fairley's help, I spent one week in Minas Gerais, shadowing at a hospital where doctors of Minas refer patients with complications from infectious diseases. I shadowed the physical therapist and the dermatology residents during sixteen leprosy consults. These consults provided twenty-first century experiences with leprosy. While there, I also visited Santa Isabel, a leprosarium in Minas. This leprosarium still houses and cares for over two hundred patients that remain there despite changes in legislation. There I gathered oral histories of patients and their families. I use the experiences of these patients to show firsthand experiences of isolation. One of the narratives from Santa Isabel was used to describe stigma during the isolationist period; the other narratives were used to detail the trauma of family separation and its longstanding effects post-isolation.

My interdisciplinary methodology shows the continuity of stigma across different mediums and across time. Seeing the many sources of stigma helps me identify potential reasons for its longevity and make suggestions for improved public health campaigns against leprosy stigmatization. Although the sources are different, I am showing the continuity of stigma despite these differences. I acknowledge that artists and the state express the stigma in distinct ways, that does not negate the presence of the theme of stigma and discrimination in these varying sources. The similarities show the many sources of prejudice against leprosy patients, creating an inescapable marginalization of patients even post-isolation laws.

Outline

I develop my argument in three chapters. Chapter I provides context and definitions for my analysis. Chapter II analyzes sources from the isolationist period (1924 to 1976) chronologically. Chapter III analyzes post-isolationist sources, focusing primarily on oral narratives. The following subsections provide an outline of key themes in each chapter.

Chapter I. In the first chapter, I introduce the definitions I will use in this thesis. I provide a brief history of leprosy, detailing key transitions in perceptions of leprosy and its treatment. I further explain the epidemiological situation of leprosy around the world and in Brazil specifically. I identify key social factors that correlate with leprosy diagnoses to help the reader better understand at risk populations. I begin to explain the social repercussions of leprosy, and then transition to specifically addressing relationships between stigma and disease. I use Goffman's definition of stigma and provide key terms for my analysis of stigma. I detail how stigma can affect patients in general to situate the reader on how stigma can further harm patients' health. I dedicate a section to explaining the many transitions in leprosy legislation. I explain the politics that harbored an isolationist stance, the structure of the leprosaria, and identify gaps in research on leprosy legislation. The first chapter is meant to provide essential context for the reader on leprosy, stigma, and legislation in Brazil.

Chapter II. The second chapter analyzes sources produced during the isolationist period from 1924 to 1976. My sources are organized chronologically. The first section analyzes an engraving as an example of the stereotypes that pushed isolationist legislation forward as a humanitarian effort to "protect" leprosy patients. The second section uses a patient's poetry from the 1930s and 1940s to elaborate on the patient experience in leprosaria during isolation. The poetry's themes develop the diverse origins of the stigma of leprosy. The third section focuses on a public health poster released between 1935 and 1969 and an account from a medical record. These two sources mark government control of human bodies, keeping patients powerless and emotionally and geographically distant from the rest of society. To further explain the impact of leprosy on families during isolation, I use a patient narrative in my fourth section. I distinguish between the role of stigma on perceptions of leprosy as an intrinsic personality trait and perceptions of leprosy as an extrinsic bacterial infection affecting a person. My final section of the chapter analyzes João Guimarães Rosa's references to leprosy in short stories. In his portrayals, Guimarães groups leprosy with other stigmas and provides an empathetic approach, humanizing patients. The chapter expresses the effects of institutional stigma on other stigmas and therefore, patients' overall experiences with leprosy. Patients and their families still suffer the repercussions for isolation today; thus, while legislation removed the institutional stigma in 1976, its effects continue to take their toll on patients' quality of life.

Chapter III. The third chapter focuses on post-isolation stigma (1976 to 2018). I introduce Federal Ordinance No. 165/BSB which outlawed isolation of leprosy patients in 1976. I detail the role of the non-profit Movement of Reintegration of People Impacted by Hansen's Disease (MORHAN) in the financial and social rehabilitation of patients and their families. I first analyze the intergenerational effects of isolation, using narratives of the children of leprosy patients that were isolated. I specifically focus on child abuse, irreparable trauma, and consequently, inescapable poverty for the children. My next section looks at biblical stigma after 1976. I analyze a patient's portrayal of leprosy as a condemnation in his painting and the Pope's portrayal of leprosy as a condemnation in speeches. My third section uses patient narratives from 2017 and 2018, emphasizing hiding unpleasant symptoms. I further explain how lack of knowledge of leprosy symptoms, even among the medical community, can leave patients vulnerable to modern-day isolation and stigma. I then use three narratives to show how widespread misinformation (among professionals and families) can lead to patients' fear of rejection. I dedicate a section to explaining the vicious cycle of poverty and disease using two patient narratives. I conclude by emphasizing a need for a multidisciplinary approach to mitigate the stigma of leprosy, employing pop culture, clinical training, and government publications.

Conclusions. I conclude by identifying the common themes related to stigma throughout both chapters: biblical allusions, family, symptoms, and poverty. I then provide recommendations for future efforts to end the stigma of leprosy and ideas for future research questions.

Chapter I: Leprosy, Stigma and Legislation

This chapter contextualizes leprosy and provides working definitions essential to the analysis. The first section, “What is Leprosy?,” provides a brief history of leprosy, a description of leprosy today, and the epidemiology of leprosy in the world and in Brazil. The second section, “Stigma and Disease,” defines stigma and clarifies its relationship with disease. The final section of the chapter, “Leprosy Legislation in Brazil,” explains the events leading up to compulsory isolation of leprosy patients, the decree that established isolation, the structure of leprosaria, and the outlawing of isolation. These sections provide the necessary background information on leprosy, stigma, and legislation to understand my analysis in the next two chapters.

What is Leprosy?

The definition of leprosy has changed over time. As biology has progressed, the definition has become more and more precise. Biological leprosy, however, is not the only relevant delineation. Religious portrayals and stereotypes play a key role in perceptions of leprosy, creating a variation of perspectives between the medical community and popular culture.

In the Old Testament, leprosy is described as a spiritual uncleanliness or punishment for sin (Cule, 1999). Representations of leprosy often relate to the biblical representation. Some are quick to assume the stigma we see today comes from the Bible. However, the stigma of leprosy is a global phenomenon that occurs in Catholic (e.g. Brazil) and non-Catholic countries (e.g. India and Indonesia) alike. Aretaeus of Cappadocia (AD 150-200) was “one of the greatest medical scholars of Greco-Roman antiquity after Hippocrates”(Tekiner, 2015). Aretaeus of Cappadocia’s (AD 150-200) classical description of the disease says, “And since [those infected with this disease] are like this, who would not shun them, or who would not turn away in disgust, even if he were a father, or a son, or a brother?” (Cule, 1999). The stigma of leprosy stems from many sources: the bible, quarantine measures, fear of contagion, and even the patients themselves.

The biblical and Greek representations show leprosy as a disease of the soul instead of the body. Thus, the disease impacted the patient physically and socially, leaving them disabled and socially outcasted. In the nineteenth century, Europe accepted Dr. Daniel Cornelius Danielssen and Dr. Carl Wilhelm Boeck's theory that leprosy was a hereditary disease. In 1873, Armauer Hansen, one of Danielssen's students, saw the bacillus under a microscope. He claimed that the bacteria were the causative agent for leprosy and that leprosy was "neither a hereditary disease nor a curse given by God that lepers must suffer for their sins"(Ghosh & Chaudhuri, 2015). The medical community, however, did not readily accept Hansen's revolutionary conclusions. Hansen was one of the first researchers to even suggest that microorganisms could cause human diseases(Ghosh & Chaudhuri, 2015). Despite the backlash Hansen received at the time, today we know bacteria do in fact cause leprosy.

Physicians used to include many diseases under the umbrella term of "leprosy." Dr. Hansen's discovery helped specify the disease to a specific bacterium. Leprosy, today, is a chronic infectious disease that affects the skin, peripheral nerves, respiratory tract and eyes. Approximately 95 percent of the world population is naturally immune to leprosy ("Hansen's Disease (Leprosy): Transmission," 2017). The factors that make the other 5 percent vulnerable to the bacteria are unknown. The bacteria that causes leprosy grows slowly; thus, the average incubation period for the disease is five years but ranges from nine months to twenty years[1] ("Frequently Asked Questions on Leprosy," 2013). The long incubation period makes it difficult

---

[1] The Center for Disease Control defines incubation period as the period from the time of exposure to the bacteria to the onset of symptoms ("Lesson 1: Introduction to Epidemiology, Section 9: Natural History and Spectrum of Disease," 2012).

for public health researchers to pinpoint precise reasons for lack of immunity. Researchers, thus, rely on correlative data to identify populations at risk for the disease.

Physicians usually diagnose leprosy through a patch of discoloration with lack of sensitivity. The diagnosis is sometimes confirmed with a skin or nerve biopsy to check for bacterial counts. However, the skin smear only confirms some cases; some patients with leprosy have negative skin smears despite having the disease. Thus, curing patients depends on the physician noticing the symptoms of leprosy without test results and then prescribing a cocktail of three antibiotics (Multidrug therapy). Multidrug therapy (MDT) does three things: it cures leprosy, it stops the patients from spreading the disease to the five percent that are not immune, and it prevents disability for the patient. The World Health Organization recommends between 6 months and a year of treatment to cure the disease("Essential Medicines and Health Products Information Portal: Treatment of Leprosy," 2017). The Brazilian government follows these recommendations.

Doctors often misdiagnose leprosy initially. Delayed diagnosis (and therefore delayed treatment) is a continuous challenge for both disease prevention and treatment. Untreated leprosy can lead to scarring, loss of eyesight, and loss of nerve sensitivity, particularly in the limbs. During my time in Brazil, I saw several cases of disability that could have been avoided with a timely diagnosis. I particularly remember a woman who went to the hospital asking to have her severely disfigured foot amputated after being misdiagnosed and poorly monitored by her physician (See “Preventable disability and stigma: Fernanda’s narrative” in Chapter III). Amputations, blindness and disability are preventable with treatment, but at times, doctors are ill-prepared to identify the disease. Thus, the disease advances and does irreparable damage to the patient.

The WHO considers leprosy a “neglected tropical disease” (NTD) ("Neglected tropical diseases," 2018). NTDs are a group of communicable diseases that prevail in tropical and subtropical conditions that worst affect populations living in poverty("Neglected tropical diseases," 2018). Water contamination, poor living conditions and inadequate hygiene and sanitation propagate these diseases. These conditions put those in poverty at a greater risk for disease. There is a correlation between incidence of leprosy and poor, crowded living conditions. The WHO’s Weekly Epidemiological Record, a quantitative epidemiological record of disease counts by country, showed 210,617 newly detected cases of leprosy in 2017 (*Weekly Epidemiological Record: Global leprosy update, 2017*, 2018). 94.8 percent of those cases were in only twenty-two of the 150 countries that reported to the WHO (*Weekly Epidemiological Record: Global leprosy update, 2017*, 2018). Brazil and India alone accounted for almost three-quarters of the new cases worldwide (*Weekly epidemiological record: Global leprosy update, 2016*, 2017). In fact, Brazil has consistently had the second-most number of detected cases of leprosy for the past decade (*Weekly epidemiological record: Global leprosy update, 2016*, 2017).

In 2016, Brazil had 25,218 newly detected cases(*Weekly epidemiological record: Global leprosy update, 2016*, 2017). Table 1 compares population, the number of new cases, the number of children among new cases, and the number of new cases with grade-2 disability in Brazil and four other countries. Pediatric cases and high rates of grade-2 disability at diagnosis indicate high risk areas for the disease. Leprosy rarely occurs in children under the age of sixteen, in part because of its long incubation period but can also be due to inherent immunity at birth to the bacteria. High numbers of pediatric cases suggest a large volume of the bacteria circulating in the community. Grade-2 disability at diagnosis correlates with delays in diagnosis, often caused by initial misdiagnosis. I remember the many cases that physicians had misdiagnosed while I was in Brazil. The consistently high number of detected cases in Brazil does not capture those cases that physicians are yet to identify. In comparison to Mexico,and Pakistan, Brazil had a much larger number in general, pediatric cases, and grade-2 disability cases. Brazil has particularly high incidences of leprosy in comparison to other countries with comparable population sizes.

Table 1. Comparing New Cases of Leprosy in Brazil to Other Countries

Country	**Population**	**Number of new cases in 2016**	**Number of children among new cases**	**Number of new cases with grade-2 disability**
Brazil	209,288,278	25,218	1,696	1,736
India	1,339,180,127	135,485	11,792	5,245
Mexico	129,163,276	152	3	8
Pakistan	197,015,955	397	38	61
United States	324,459,463	168	Not Reported	Not Reported

Table 1. I gathered the data from the WHO's Weekly Epidemiological Report 2016. The chart situates Brazil's situation by allowing comparisons with other countries. India has the greatest number of new cases worldwide and is succeeded by Brazil. I included the United States, Mexico, and Pakistan for comparison with countries of similar population sizes, development classification, and/or world region. In comparison to Mexico, Pakistan, and the United States, Brazil had a much greater number of new cases. Furthermore, Brazil had a much larger number of pediatric cases and grade-2 disability cases than Mexico and Pakistan. For comparisons with other countries, please refer to the WHO's Weekly Epidemiological Report or see Appendix A for a map of new leprosy cases.

Considering Brazil's large population, I looked at how Brazil's prevalence rate for leprosy compared to the rest of the world. The epidemiological prevalence rate of a disease is the number of registered cases per population. In 2016, the WHO found an overall 0.23 per 10,000 prevalence rate of leprosy from the 143 reporting countries. Similarly, the Americas WHO Region had a 0.31 prevalence per 10,000 population (*Weekly epidemiological record: Global leprosy update, 2016*, 2017). Brazil, however, had a 1.09 prevalence rate per 10,000 population in 2016. The stark difference between the global prevalence rate and Brazil's prevalence rate show that, apart from being a large contributor to the number of new cases, Brazil has a higher than average number of cases per capita.

Within Brazil, the greatest average detection rates from 2012 to 2016 were in the Centro-Oeste (3.73 per 10,000 population) and Norte (3.43 per 10,000 population) regions[2] (*Boletim Epidemiológico: Hanseníase*, 2018). All states, except Rio Grande do Norte, showed higher detection rates among males. Of the 95.7 percent of cases that self-reported their race, there was a higher percentage of mixed and black patients (71.7 percent) in comparison to the other racial groups (white: 26.8 percent, yellow: 0.9 percent, and indigenous: 0.4 percent). As for levels of education, a majority (55.0 percent) of the reported cases between 2012 and 2016 were illiterate and had not completed elementary school. The high illiteracy rates and racial disparities among leprosy patients suggests the disease's correlation with the underprivileged social classes.

As I showed with the number of new cases and the prevalence rate of leprosy, leprosy is more common in Brazil than in other countries. However, leprosy is uncommon relative to other diseases in Brazil. The Joint United Nations Programme on HIV/AIDS estimated 48 thousand new HIV infections in Brazil in 2017, almost double the number of new leprosy cases("AIDSinfo," 2018). Research from 2012 suggested that about 30 percent of Brazil's population had hypertension (approximately 60 million patients)(Picon, 2012). The International Diabetes Federation estimate 12.5 million people were living with diabetes in Brazil in 2017 (*IDF Diabetes Atlas*, 2017). The incidence of leprosy is much smaller than that of HIV, hypertension, and diabetes. Despite the smaller number of cases and an available cure to the disease, the stigma of leprosy continues to impact patients.

In 2016, WHO published the Global Leprosy Strategy which sets the goals of: zero disability among new pediatric patients, a grade 2 disability rate of less than 1 case per million

---

[2] The Ministry of Health in Brazil defines detection rates as the number of newly diagnosed cases per population per year (*Boletim Epidemiológico: Hanseníase*, 2018).

and zero countries with legislation allowing discrimination on the basis of leprosy by 2020[3] (*Global Leprosy Strategy 2016−2020: Accelerating towards a leprosy-free world*, 2016). The third pillar of the Global Leprosy Strategy refers to the social repercussions that follow a leprosy diagnosis. In a research study by Anwei Skinses Law's research study for the International Association for Integration, Dignity, and Economic Advancement, Francisco A.V. Nunes, a Brazilian afflicted with leprosy, shares:

> To many of us worse than the very disease is the prejudice that comes along with it. Many of us stopped being called Francisco, Joe, Maria, and we started being called leprosy patients, 'lepers' and recently Hansenites….I believe that our greatest challenge is to make sure that millions of people who have lost their identities will go back to being called by their own names. (Law, 1999)

Accounts like these show that, despite the treatment of physiological symptoms with MDT, the psychological and social consequences of being diagnosed with leprosy are yet to be resolved for many patients.

Stigma and Disease

Goffman defines social stigma as "an attribute that reduces the person from a whole and usual person to a tainted, discounted one, especially when its discrediting effect is very extensive"(Goffman, 1986) The sociologist argues there are three types of stigma: abominations of the body, blemishes of individual character, and tribal stigma (such as race, nation, religion). Phelan, a medical sociologist, defines three key uses for stigma: deviant behavior and identities,

---

[3] The WHO grades leprosy patients according to their level disability in their hands, feet and eyes (Brandsma & Van Brakel, 2003). Grade 0 is no anaesthesia and no evidence of visual loss. Grade 1 is anasthesia without visible deformity or damage to hands and feet and/or eye problems present but vision not severely affected. Grade 2 is visible deformity or damge present and severe visual impairment.

norm enforcement, and disease avoidance (Phelan, Link, & Dovidio, 2008). Stigma is applied at individual, interpersonal, and structural levels (Link & Phelan, 2001). Individual stigma occurs through personal, cognitive and behavioral responses(Link & Phelan, 2001). The individual can discredit themselves according to an insecurity; this is sometimes called self-stigmatization (Watson, Corrigan, Larson, & Sells, 2007). Interpersonal stigma is discrimination from the un-stigmatized individual to the stigmatized individual. Structural stigma includes cultural norms and institutional policies that limit the opportunities, resources and well-being of the stigmatized person.

Stigmatized diseases --such as HIV/AIDs, mental disorders, and leprosy—have clinical and social repercussions for patients. A physical therapist in Brazil told me that doctors in Brazil specifically advise their patients to keep their leprosy a secret from everyone but family. The visibility of symptoms, however, can expose patients to stigma despite patients' and healthcare providers' efforts to keep diagnoses secret (Goffman, 1986). This exposure leads to social isolation, affecting the person's quality of life. The WHO defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"("Health statistics and information: WHOQOL: Measuring Quality of Life," 2018). For example, Huing Ma *et al*. identified stigma as a key determinant in the quality of life of people living with Parkinson's disease(Ma, Saint-Hilaire, Thomas, & Tickle-Degnen, 2016). Findings like Huing Ma's can inspire measures against stigma. In the case of leprosy patients, the United Nations Human Rights Office appointed a Special Rapporteur advocating for the dignity, human rights and fundamental freedoms of people affected by leprosy and their family members ("Elimination of discrimination against persons affected by leprosy and their family members," 2015). Despite these key steps to condemn the discrimination against patients, the stigma of leprosy still exists today.

Goffman's definition of stigma is particularly useful in understanding the persistent discrimination against people with leprosy because it includes the visibility of stigmatized attributes as a determinant of discrimination. Several of my sources show patients feeling diminished by leprosy or experiencing discrimination. Link and Phelan's explanation of the levels of stigma and the motives for stigma supplement Goffman's definition. In the case of leprosy, the stigma falls under Goffman's category of abominations of the body. Likewise, the motive for the stigma falls under what Link and Phelan describe as disease avoidance. Together, these definitions explain the stigma of leprosy for the purposes of this project.

Leprosy Legislation in Brazil

Because of stigma and the prevalence of leprosy among low-income social classes, the stereotypical image of leprosy is a disfigured beggar. In the early twentieth century, nomadism was a typical lifestyle for leprosy patients in São Paulo. They roamed the streets in groups asking for money, since business owners deemed them unemployable (Monteiro, 1987). The state government and public health officials saw leprosy as a barrier to modernity (de Castro Santos, 2008). Defenders of isolation justified it as "social assistance" for patients and protection for the rest of society (de Castro Santos, 2008). In theory, the patients in isolation would live in communities of people like them instead of being subjected to daily discrimination in society.

Officials engaged in polarized discussions on how to control the spread of the disease. In 1916, Emilio Ribas, a public health leader in infectious disease control, stressed isolation of poor, contagious cases. He advocated for mandatory isolation of poor and contagious cases in installations "capable of being sought out spontaneously by patients" (Ribas, 1916). Ribas claimed that treatment centers should be easily accessible to friends and family to prevent people from knowingly avoiding diagnosis. A different group advocated for unconditional isolation of anyone diagnosed with leprosy; disregarding type, contagion, and socioeconomic class. A third, group supported isolation on islands like Ilha Grande. The lack of knowledge of the transmission of leprosy drove isolationist public health policy. São Paulo implemented unconditional isolation of patients diagnosed with leprosy.

In 1923, the federal government promulgated Decree No. 16.300, also named after renowned physician-scientist Carlos Chagas, for the "general and specific prophylaxis of communicable diseases", including leprosy, tuberculosis, and sexually transmitted disease ("Decreto N. 16.300," 1923). Article 4 established inspectorates for their goals under the decree. In these inspectorates, leprosy was grouped with sexually transmitted disease in the *Inspectoria de Prophylaxia da Lepra e Doenças Venereas*. Isolation could be done in government institutions, private institutions approved by the government, or at home for special cases. The conditions for domiciliary isolation were unclear, leaving decisions at the state departments' discretion. The legislation also called for *preventorios*. *Preventorios* were centers that housed the children of leprosy patients. No parent diagnosed with leprosy had a right to their child under the federal decree. The sanitary police would remove the children and place them in these leprosy-specific orphanages. The federal government funded the construction of all leprosaria and *preventorios* except those in São Paulo, which were state-funded (de Castro Santos, 2008).

The leprosaria were located in agricultural areas ("colonias agricolas"), but the residential spaces were surrounded and locked. People engaged in social phenomena like recreational activities, marriages, movie showings, and gambling (Appendices show photographs of albums of these activities). The communities included medical facilities, recreational pavilions, churches, jails, town halls, theaters, casinos, cemeteries, and houses. Women were kept in separate infirmaries from men. Eventually, the state built small houses for the married couples within the leprosaria. Within their gates, the leprosaria resembled small towns more than they did health facilities. The leprosaria even had their own circulating currency, stamped for differentiation from notes outside of the leprosarium (Fontoura, Barcelos, & Borges, 2003).

The Carlos Chagas reform established general standards for prophylaxis, treatment and funding, but disease control still functioned as a state power until 1941. Since certain states had stricter regulations than others, policy differences may explain the stark differences in isolated cases between states at the time (Appendix B). In 1941, Decree No. 3171 made prophylactic measures a federal issue(de Castro Santos, 2008). The Decree organized health services by illness: yellow fever, malaria, cancer, tuberculosis, mental illness, and leprosy. It created the *Serviço Nacional de Lepra*, responsible for technical instruction and public and private activities related to leprosy.

Simultaneously, American researchers discovered sulfone treatment, a cure to leprosy that stopped the spread of the disease, in 1941. In 1944, doctors in Brazil began to use sulfone drugs to cure leprosy (Opromalla, 2011). The promising results of the new treatment sparked discussion about compulsory isolation and the potential for treatment in dispensaries at the Fifth International Leprosy Congress in Havana, Cuba in 1948 (Opromalla, 2011). Ten years later at the Seventh International Leprosy Congress in Tokyo, isolation was condemned as “anachronic” and insufficient for curing or minimizing advances of the disease (Opromalla, 2011). In the 1940s and early 1950s, the United States loosened leprosy legislation, allowing for outpatient treatment and quicker releases (Sato & Frantz, 2005). Nonetheless, the United States enforced isolation until 1960 (Sato & Frantz, 2005).

In 1962, Federal Decree No. 968 ended the compulsory isolation of leprosy patients in Brazil at a federal level. This, however, did not change state legislation on leprosy. São Paulo continued to isolate patients under State Law No. 610 until 1967 (Opromalla, 2011). In 1976, Federal Decree No. 968 was revoked and replaced by Ordinance No. 165/BSB, completely outlawing compulsory isolation and establishing outpatient treatment. Despite the outlawing of compulsory isolation, many patients chose to stay in the leprosaria. They had made a life for themselves in the leprosaria, and now had no family nor home to go to. In Brazil, leprosaria still house these patients and are now called "hospitals."

Conclusions

As one of the oldest known human diseases, clinical aspects of leprosy have changed significantly throughout history. The classification of leprosy has become more precise, going from the biblical and Greek perception of leprosy as a "spiritual" disease to Hansen's biological definition of leprosy as a bacterial infection. Since 1941, leprosy has been curable by sulfone treatment and researchers now know that only 5 percent is susceptible to the bacteria. The many clinical and epidemiological advances related to leprosy, however, have not ended the stigma of leprosy. Patients are still affected by biblical stereotypes and discrimination today.

Furthermore, leprosy legislation in Brazil isolated patients for thirty-two years after doctors started to prescribe sulfone treatment, a cure to leprosy. Isolation distanced society from the disease and traumatized patients, reaping longstanding repercussions for leprosy patients and their families. Even after isolation was outlawed in 1976, many patients chose to stay in leprosaria because of a lack of options elsewhere. Institutional stigma ended in 1976, but interpersonal and self-stigma continue even today.

Stigma has repercussions on clinical care. It affects patient quality of life, can lead to severe psychological trauma, and can deter patients from seeking a diagnosis. Furthermore, stigma can create a vicious cycle of poverty and disease. The stigma of leprosy is ancient and continues to hinder the lives of patients today. The context in this chapter will help the reader understand the arguments developed in other chapters on the stigma of leprosy and its impact on patient experience.

Chapter II: Isolation (1923-1976) Fortified the Stigma of Leprosy

This chapter focuses on the stigma of leprosy during the compulsory isolation of leprosy patients (1923-1976), focusing on the interplay between institutional stigma enforced by government legislation, interpersonal stigma, and self-stigma (See “Stigma and Disease”, Chapter I). The sections are organized chronologically by source.

The first section, “Leprosy Stereotype for a Political Agenda: Brocos’s engraving,” uses Modesto Brocos’s engraving, *Saint Elizabeth Queen of Hungary curing the lepers as per Murillo,* to elaborate on leprosy stereotypes as public health officials crafted isolationist legislation. I specifically develop the relationships between race, social classes, and leprosy.

The second section, “Stigma has Diverse Origins: Gonçalves’s Poetic Examples,” uses a patient’s poetry from the 1930s and 1940s to show the many sources of leprosy’s stigma: biblical stigma, self-stigma, and structural stigma via family separation.

In the third section, “Government Control of Human Bodies: Prophylaxis Poster and Julia’s Medical Record,” I use a public health poster and an account from a medical record to establish the vulnerability of patients and the government’s emotional and geographical distancing of patients from the rest of society.

The fourth section, “Stigma Overcomes Family: Maria’s Oral Narrative,” focuses on a patient’s experience with leprosy, detailing how she recalls her family’s perceptions of her diagnosis. This section develops the consequences of stigma when leprosy is interpreted as an inherent personality trait and conversely, an extrinsic factor affecting a loved one.

The fifth section of the chapter, “Prioritizing Empathy Instead of Stigma: Guimarães’s short stories,” analyzes João Guimarães’s inclusion of leprosy in two short stories, particularly his comparison of leprosy’s stigma with other stigmas and his empathetic portrayal of patients.

Through these diverse sources, I gather details on the patient experience of leprosy during isolation and establish how discriminatory legislation (institutional stigma) affected self-stigmatization of patient and interpersonal stigma between family members, social classes, and others. The constant interaction between the levels of stigma created a particularly difficult situation for leprosy patients with longstanding effects on patients, their families, and generations to come.

Leprosy Stereotype for a Political Agenda: Brocos's Engraving

This section uses Modesto Brocos's engraving *Saint Elizabeth Queen of Hungary curing the lepers as per Murillo* to explain the stereotypes that existed of leprosy patients as isolationist policies began in the 1920s (See Appendix C for engraving). Brocos's depiction aligns with the justifications politicians and public health officials used to compulsorily send patients to leprosaria. Brocos plays on stereotypes to create a clear social hierarchy with leprosy patients encompassing the lowest social-class. Some of the stereotypes continue to affect patients today, particularly the biblical allusions to leprosy as a punishment for sin.

In 1889, Brazil became a republic. This change led to many new cultural and political ideologies. Basing themselves on racial Darwinism, law schools, medical schools, and museums expressed fear of the racial "situation" in Brazil (Schwarcz). By the turn of the twentieth century, the country underwent a period of advocacy for whitening (*branqueamento*). Many historians say government policies sought to whiten the Brazilian population by attracting European immigrants to Brazil and encouraging interracial procreation (Schwarcz, Skidmore). Brazil received almost 3.8 million immigrants, mainly European and Asian, between 1887 and 1930 (Fausto). The arts reflected the racial whitening phenomena at the time. Fausto describes the arts in 1889:

> "as a historically unique opportunity to transform Brazil into a modern country, more aligned or at least a little closer to the setting of modernization of the European countries"
>
> "*como uma oportunidade histórica única para transformer o Brasil num país modern, mais alinhado ou pelo menos um pouco mais próximo do cenário de modernização dos países europeus*" (Saliba).

Among those immigrants arriving in Brazil was Modesto Brocos y Gomez (1852-1936), a Spanish artist. He gained recognition in 1911 when Joao Baptista de Lacerda, a physician and anthropologist, presented his painting, *The Redemption of Ham,* in the First World Congress on Race to show that racial mixing would resolve Brazil's problems with race. The painting shows a black grandmother's celebration of her mulatta daughter's white baby alongside the daughter's white husband. Lacerda highlighted the whitening of the Brazilian population through interracial marriages in the conference and used the painting as an example of Brazil's future. Today, the painting is still analyzed by sociologists, anthropologists and art historians for its dated depiction of race.

Social hierarchy and disease. In the early nineteenth century, Brocos made the lesser known *Saint Elizabeth Queen of Hungary curing the lepers as per Murillo* (*Santa Izabel Rainha da Ungria curando os leprosos segundo Murillo)*. I found the small engraving (30.3 cm x 22.5 cm) in the digital archive of the National Library of Brazil. Murillo titled the original version from the seventeenth century, *Santa Isabel de Hungría curando a los tiñosos*. Brocos's version is an exact copy of Murillo's large oil painting on canvas; he did, however, change the disease in the title from ringworm to leprosy. This change shows the lack of distinction between the diseases of the poor and suggests the inevitability of disease for the impoverished, darker skinned populations. This, in turn, fortifies misconceptions of leprosy and propagates the stigma that already exists.

In the engraving, Brocos glorifies Saint Elizabeth, a thirteenth century Hungarian princess canonized by the Catholic church for her devotion to the poor ("Saint Elizabeth of Hungary," 2018). Her position in the center of the piece and her clothing are reminiscent of Virgin Mary. She has a fair complexion and wears a crown and a halo as she washes a scarcely dressed, barefoot boy's head in a washbasin. A nun and two lavishly dressed women assist her. One of her assistants carries a pitcher with water; the other carries a small cup and a flask, seemingly medicine.

Brocos represents the glorification of the white race and the difference in social classes within Brazil. He presents the characters hierarchically placing them at different heights. The queen, her helpers, and the nun are the highest in the engraving. The "lepers", as described in the title of the painting, are all below them representing the subjugation of the low-income classes to the will of the upper class. Saint Elizabeth directs her gaze downward at an older woman sitting on the ground. The woman sitting on the ground is barefoot with a broken dress and walking stick. Also on the ground, a man bandaging a lesion on his leg. A bearded man with two crutches and an injured leg crouches and looks towards Saint Elizabeth. Those on the ground are in a vulnerable position and depend on the aid of those in power, in this case Saint Elzabeth.

The two sick men and one of the boys are of darker complexions, linking disease and poverty to black Brazilians. Lack of grooming, clothing and/or shoes differentiates the sick characters from the upper class in the work. Public health statistics still show correlations between leprosy and mixed or black races in Brazil (See "What is Leprosy?"). This correlation, however, does not clarify whether there is a genetic predisposition for susceptibility to leprosy among these classes or higher rates of poverty among black or mixed peoples that account for these correlations. The portrayal of leprosy as a disease of the poor and black populations in the engraving shows these correlations, but also further subjects these populations to discrimination and stigma by labelling them a diseased population.

Brocos's twentieth century engraving indirectly references the biblical representation of leprosy. The princess cleans the leper as Jesus miraculously cleansed a leper in the Gospel of Matthew. Even today, some people view leprosy as a biblical curse. Nations *et. al*'s ethnographic research notes the journey Marta, a Catholic patient, suffered. She recounted immediately linking her diagnosis with Hansen's disease to biblical leprosy (Nations). She directly read passages to the interviewer from the bible on the isolation of "lepers" and expressed the shame she feels because of her diagnosis. Marta is an example of the patients who struggle with their diagnosis because of their religion and stigmatize themselves. The biblical description of leprosy is undoubtedly a contributor to leprosy's stigma and its continuity. Brocos propagates that stigma by depicting the patients as a social burden, inferior to the helpful, white, European queen in his engraving.

Art Historian Rafael Cardoso claims that Brocos's other piece, *The Redemption of Ham*, was welcomed by elites as a "progressive message" for its focus on racial mixing instead of racial segregation. Cardoso considers, "Remarkably from the vantage point of today, it was lauded precisely for its progressive message [in 1895 ...] For all the racism the image undoubtedly expresses, it manages paradoxically to free itself of any trace of stereotype" (Cardoso 2015). Likewise, in *Santa Izabel Rainha da Ungria curando os leprosos segundo Murillo*, Brocos depicts race and class relations positively by representing the white European aiding the sick, impoverished characters. Nonetheless, the work represents the racial and social inequality of Brazilian society in the early twentieth century. It establishes power differences and stereotypes those that suffer leprosy as mixed race or black, poor, and helpless. These stereotypes persist in society. In fact, Candido Portinari, a Brazilian painter, biblically portrayed leprosy patients as impoverished, disabled and suffering in a mural from the 1945 at the São Francisco de Assis Church in Belo Horizonte, Minas Gerais (See Appendix D).

Final thoughts on leprosy stereotype for a political agenda. The perception of leprosy patients as suffering, as seen in Brocos's engraving and Portinari's mural aligns with the rationale used by Brazilian public health officials to justify federal isolationist measures in 1923. The policy follows the Old Republic's positivism of "order and progress." The government made efforts to become a "modern" nation by prioritizing sanitation and a healthy population[4]. The sanitation regulations, including leprosy legislation, allowed the state to control the bodies of the public. In the 1920s, leprosy patients were often left homeless by their disability and the stigma of the disease. Without the knowledge of the population's general immunity, legislators approved Federal Decree No. 16.300 in 1923 to isolate leprosy patients everywhere in Brazil. This policy propagated misconceptions and ignorance on the true nature of the disease; educating the public on leprosy is still a challenge in Brazil.

Stigma Has Diverse Origins: Gonçalves's Poetic Examples

Brazil continued to finance leprosaria despite the global market crash of 1929, demonstrating the government's emphasis on health policy. I visited two of the leprosaria, Pirapitingui (São Paulo state) and Santa Izabel (Minas Gerais). As I strolled along the dirt road within Pirapitingui's gates, I noticed the words "Jesus Gonçalves-Poet" painted on a small house.

---

[4] For an example of this, read about the 1904 Vaccine Revolt (Caldeira, de Carvalho, Marcondes, & Goes de Paula, 1997)

I immediately took note of the poet and local hero for my thesis. Through his poems, I am able to analyze the internal struggles of a leprosy patient from the isolationist period. His poetry incorporates themes like disfiguration and religion, self-stigmatization, and solitude and family. I analyze each of these themes in subsections for this section of Chapter II.

He was born in 1902 to poor parents in Borebi, São Paulo (Gonçalves, 2009)[5]. His parents were unable to financially support his education, but he read educational materials from home. Gonçalves's upbringing in a low socioeconomic status household and his lack of elementary education fits the typical case of leprosy. Throughout his adult life, Gonçalves worked as a treasurer of the Municipality of Baurú. In 1930, doctors diagnosed him with leprosy. Following his diagnosis, police took Gonçalves to Aimores asylum-colony in Baurú, São Paulo, forcing him to leave his job as treasurer. For health reasons, doctors transferred him to Pirapitingui, another leprosarium in the state of São Paulo, in 1937. Gonçalves was a leader, starting newspapers in both leprosaria and a radio station in Pirapitingui. Apart from these projects, he occupied his time writing poetry.

Gonçalves was an atheist, but during his time in isolation, he turned to *espiritismo*, a religion that uses mediums as the conduit between the higher spirits and the faithful ("Espiritismo,"). Nonetheless, he at times alludes to Catholic portrayals of leprosy. He died in 1947, but the *espiritas* believe he sent messages through the spirit of Francisco Cândido Xavier, a popular figure and medium in *espiritismo*. For the purposes of this project, I only used the

---

[5] The biographical information on Gonçalves was written by someone from Pirapitingui. This person is unspecified, but the short biography was published in *Flores de Outono*. It is important to note that the book adheres specifically to *espirita* audiences (explained above). Since Gonçalves is a hero in this religion, the biography paints him as such. This is the only biographical information I was able to find; thus, I am limited to one source on Gonçalves's life. Although the biography is somewhat questionable, my analysis bases itself on the themes of the poetry and not the precision of these facts.

poems written during Jesus Gonçalves's isolation (1931-1947) although *Flores de Outono* includes the poems communicated through other spirits as per *espiritismo*. I was only able to find the book in an *espiritismo* bookstore in São Paulo; hence, the anthology is meant for a religious audience with the purpose of inspiring faith among *espiritas*. Gonçalves wrote several poems in Aimores and Pirapitingui; I selected those that specifically referred to his disease or isolation. These four poems show how stigma impact the patient's life. I focused on the toll symptoms of the untreated disease, religious portrayals, solitude, and self-stigmatization took on Gonçalves.

Disfiguration and Religion. Leprosy, in Gonçalves's time, was incurable. It led to severe disfigurement of the limbs and facial features, making leprosy patients an uncomfortable sight for many in the population. Goffman categorizes people with visible stigma as "discredited." Goffman describes:

> When there is a discrepancy between an individual's actual social identity and his virtual one, it is possible for this fact to be known to us before we normal contact him, or to be quite evident when he presents himself before us. (Goffman, 1986)

Untreated leprosy patients fall under this characterization, since body disfigurement becomes difficult to conceal. Gonçalves speaks of the physicality of the disease in "Crying" ("Chorando")(Appendix E). He describes leprosy as a "wounding and damned plague [… that] sticks by marking." He uses the word "chagosa", which in Portuguese implies a wound that does not heal. The damage done by the bacillus is irreversible. Even today, medicine can only kill the bacteria and stop it from further harming the patient. The disfiguration's permanence leaves Gonçalves with less hope of separating his identity from the disease.

Gonçalves's use of "plague" alludes to the Black Plague of the Middle Ages, tying leprosy to both contagion and tragedy. The perception of leprosy as contagious contributes to its stigma. The fear of contracting the disease from contact with a patient drove isolationist policy and still socially isolates patients today. A physical therapist recounted a patient's struggle to find a dentist that would tend to his toothache (See Tiago's narrative in "Battling Widespread Misinformation", Chapter III). His dentist saw his condition and the medications he was on his medical chart, and immediately, told him he could not return to the clinic because he was "contagious." The dentist's refusal of the patient shows that ignorance of the true nature of the disease exists across all levels of education. As with this case, ignorance can subject patients to unnecessary discrimination, affecting their quality of life, mental health, and self-esteem.

In Gonçalves's description, he directly links the physicality of the disease to religion by using "wounding" and "damned" next to each other. He describes the spreading of the disease with the verb "pregar-se" which means to nail or to preach. This play on words shows the disease as something he is stuck with while alluding to the stigma Catholicism preaches about leprosy. Interestingly, Gonçalves, an atheist at the time, still alludes to the biblical association of leprosy and damnation. This shows the power and persistence of ancient biblical representations of leprosy.

Self-stigmatization. Patient awareness of stereotypes of leprosy drive the self-stigmatization of patients (Watson et al., 2007). Patients internalize discrimination and begin to isolate themselves from others, leading to lower self-esteem (Watson et al., 2007). Isolation fortified stigma from both external and internal sources in leprosy patients. Cassandra White, an anthropologist from Georgia State University, witnessed self-stigmatization in 2012 in a leprosarium in Rio de Janeiro. She noticed that older patients that had suffered isolation identified themselves as sick even after being cured while newer patients stopped considering themselves sick after finishing antibiotics. Self-stigma has longstanding, profound effects on patients' mental health. Gonçalves shows this in his poetry by labelling himself a leper and stigmatizing himself. He shows how he perceives himself as diseased, impure, and guilty because of leprosy.

In "Confidence" ("Confidência"), the poet parallels his longing for liberty with that of a canary (See Appendix E). The poem shows leprosy as a justification for confinement and the impact isolation can have on the self-perception of patients. Gonçalves says, "I am sorry you were given the same luck, that your Innocence supports the same pain, when you are not even a leper." Here, he stigmatizes himself once again. He juxtaposes the bird's innocence with his identity as a leper. This suggests that the disease taints innocence and purity, an allusion to the biblical representations of leprosy. The "leper" is blamed for his disease and portrayed as more deserving of incarceration than an "innocent canary." The juxtaposition of leprosy with an "innocent" canary indirectly suggests that isolationist policy is justifiable. This shows how isolation shaped how patients perceived themselves and promoted self-stigmatization.

Furthermore, his self-portrayal as diseased in other poems shows how leprosy came to consume the patient's identities. In the poem "My Verses" (Meus Versos), Gonçalves describes himself as unlucky for having a heart in a sick body (See Appendix F). He says, "[…] because I was given by rough luck; a healthy heart in a sick body!" This suggests a lack of desire to live and a self-identification as sick. This self-identification as diseased is a form of self-stigmatization. Gonçalves's portrayal of himself limits his identity to his illness. His experience speaks to patients' internal conflicts with their diseased bodies and identities.

Solitude and Family. Legislators in favor of isolation envisioned a community where leprosy patients would find company and support in each other. Nonetheless, leprosy brought solitude to many patients that could not help but notice the differences between living in confinement and in their homes. The tearing apart of families made isolation difficult for patients. According to an employee I spoke with at Pirapitingui, many of the patients that still live in the leprosaria do so because they have nowhere else to go. The separation from their families made patients lose all ties outside the gates of the leprosarium. I met family members that moved to areas surrounding the leprosaria post-isolation to be closer to their loved ones. The state's separation of patients from their loved ones took an emotional toll on patients and contributed to their trauma. That loneliness fed into feelings of low self-worth and thus, led to more self-stigmatization.

"My Verses" refers to isolation as living in the "insipidity of the forgotten." In the archives at the Museum of Public Health, I saw DPL photograph albums of gymnastics tournaments, soccer tournaments, cinemas, and dances (See Appendices G, H and I). However, there is a dissonance between these representations of life in the leprosaria and Gonçalves's representation. Gonçalves sees life in confinement as bland. He specifically attributes the dullness to being forgotten. The leprosaria's locations in rural colonies meant less contact between patients and other people. Even as a researcher fifty years later, I struggled to find portrayals of these "forgotten" patients and the disease. Today when I mention my project to anyone, including Brazilians, many respond by saying they did not know leprosy still existed but recalled the body disfiguration that could occur.

Gonçalves's melancholic tone suggests the hopelessness of patients in the leprosaria. This despondency is seen again in "Crying" ("Chorando") when he says, "There was a start of happiness […] but there came a bacillus, -- what unhappiness—and the whole family started to cry!" The people that suffered leprosy in the 1940s still did not have a cure and had no expectations of being reunited with their families. Gonçalves concludes "My Verses" with "I moaned in the solitude of a desert." The poet repeats the theme of solitude throughout his time in Aimores and Pirapitingui. The moan at the beginning of the verse shows the agony of solitude. More importantly, isolation, which Gonçalves compared to a desert, is seemingly endless. The sentiment related to both the physical isolation from the rest of society and the absence of his family. The endless loneliness, portrayed in the poem, affected patients' mental health. As I met patients and asked them how long they had lived in Santa Izabel, they all responded similarly citing the exact dates the police brought them to the leprosarium. The patients had the dates engrained in their brains from the trauma of being taken from their families. The absence of hope to return to a "normal" life drove patients into depression and even suicide in some cases.

Although Gonçalves did not remarry within the leprosaria, I read in medical records and met several patients that remarried in the colonies with the approval of a doctor. I found a 1943 medical record that showed a patient's request to marry a fellow patient. An authority at the leprosarium denied their request on the basis that the patients suffered different types of leprosy, a fact that infectologists would consider irrelevant today. Soon thereafter, a report of the patients escape from the leprosarium shows up. When police caught them, the patients claimed they had runaway to marry each other. The authorities then revoked their denial and allowed them to marry. The case shows the lack of control patients had of their relationships even within isolation since they needed approval to marry each other. It also shows how arbitrary decisions dictated the criteria and regulations of isolation.

Despite the state's permission of marriages among patients, they did not allow anyone diagnosed to keep custody of their children. The state denied leprosy patients their roles as parents. The inability to be with their previous families and/or start a new family made life unbearable for some patients. Maria, a patient who was isolated in Santa Izabel, told me, "Many women committed suicide in the river after having their babies taken away" (See "Stigma Overcomes Family: Maria's Oral Narrative"). The loss of their children heavily impacted the mental health of patients in isolation, including Jesus Gonçalves. In "Extreme Misery" ("Miséria Extrema"), Gonçalves directly mentions his children, "My children!, four jewels of purity that destiny gave me as a legacy!" (See Appendix J). His comparison of his children to "a treasure" and "jewels" shows how much he valued his family. He personifies the disease by comparing it to a robber saying, "One day…a virus, a brutal robber, robbed me of my jewels." The personification gives power to the disease and victimizes the patient. He expresses the grief of losing his living children because of his lack of contact with them.

Gonçalves directly blames the "virus" for the loss of his children and does not mention the role of isolationist policy. This differs from other patients I met who blame people for their solitude and not the disease. The stigma then stems from the disease and not the people that participate in it. He does not directly mention public policy in his laments, and solely attributes the stigma he feels to the disease itself and not people's perceptions of the disease. With time and medical advances, patients would realize that the stigma stems from social misconceptions of the disease being contagious or sinful since leprosy is not a danger to society.

As Gonçalves blames the disease in his poetry, he creates a separation between the disease and himself. He emphasizes that he is a victim of the disease, but he is not defined by his disease. This differs from his self-referral as a "sick body" in "My Verses" where he is inseparable from the disease. Therefore, while in "My Verses" he participates in auto-stigmatization, he is a victim of stigma in "Extreme Misery." Gonçalves's poetry shows the battle of patients between being more than their disease and accepting the social identity of a "leper."

Final thoughts on Gonçalves. In the final stanza of "Extreme Misery", Gonçalves shows the perpetual cycle of poverty, stigma, and disease. He says, "Without the treasure of such noble value, I regret having cried for being poor, for I have never been as poor as I am now." Gonçalves was poor prior to his disease, but after his diagnosis, he lost the little that he had: his profession and his family. This, in turn, led to public- and self-stigmatization. Gonçalves's poetry speaks to his firsthand experience as a patient living in a leprosarium. He directly experienced the hardships of leprosy in the 1930s and 1940s. Gonçalves represents the sentiments and stigma patients felt during isolation in his poetry. His poems reflect the impact marginalization has on patients. He expresses sadness, loneliness, and hopelessness throughout his poems. At times, he ties his identity to the disease, limiting his life to his diagnosis. Other times, he depicts himself as a victim of the disease. This internal battle is perpetuated the external influences of stigma. Thus, the biblical stigma of leprosy, the stigma of isolation, and the self-stigmatization leprosy patients face come together to make acceptance of the diagnosis particularly difficult.

Government Control Of Human Bodies: Prophylaxis Poster and Julia's Medical Record

In 1941, Dr. Guy Faget, an American physician, started a clinical trial for a sulfone drug to treat leprosy (Sato & Frantz, 2005). The clinical trial was successful in curing leprosy. In 1944, physicians in Brazil began to prescribe sulfone drugs to patients in leprosaria. In 1946, the Conference on Leprosy in Rio de Janeiro noted "significant advances from the introduction of the sulfone group of drugs" (Sato & Frantz, 2005). This however did not change legislation in Brazil. Brazil still continued to compulsorily isolate patients. Sanitarian policy had given the government control over civilian bodies. Even with a cure to leprosy in hand, patients were powerless against government control. The state used their power to hide the unpleasant disease, creating both a physical and emotional distance between society and the patients. In addition, the hierarchy within leprosaria left patients at the will of prophylaxis directors and physicians. The distance and the helplessness of patients fortified self- and public stigma.

Keeping Patients Distant: The DPL's Poster. Isolation separated leprosy patients from society. The lack of contact with those suffering the disease perpetrated stigma by limiting empathetic relationships between the healthy people and the sick. In addition to the physical separation, the decree created a social separation by promoting civilians to report anyone they suspected of leprosy. The Department of Prophylaxis of Leprosy (DPL) of the state of Sao Paulo released a poster (c. 1935-1969) that says "Collaborate in the combat against leprosy by referring people with insensitive blemishes." The state prioritized catching patients at the expense of further stigmatizing patients. The poster "others" people with leprosy outside of isolation, making these patients social outcasts and fugitives. Posters with this approach fortify the stigma by inspiring emotional and physical distance from patients. Viewing themselves as fugitives for their disease, patients further stigmatized themselves and viewed themselves as lesser than the healthy members of society, a phenomenon we already saw in Gonçalves's poetry.

The poster establishes some parallels between leprosy patients and prisoners. In exercising their control, the government created this indirect parallel in the poster and in the treatment of patients. The patients who escaped leprosaria faced consequences when they returned. The leprosaria had their own jails and court systems to sentence those who ran away. I saw several medical records citing escapes from leprosaria. I visited the jail in Santa Izabel, which was transformed into a small home post-isolation. Furthermore, Santa Izabel was surrounded by a river, a natural barrier that made it difficult for patients to escape. Across the river, on a hill overlooking the leprosaria, the state built a prison. As I strolled through Santa

Izabel, I saw the prison on the hilltop. The physical proximity of the prison exemplifies the association of the patients with criminals. In fact, the United States government went one step further after outlawing isolation and housed white-collar criminals with remaining patients to fill the Carville center.

The association of patients with criminals put patients at fault for their disease. The state physically isolated patients but, more importantly, distanced patients emotionally from the rest of society strengthening the stigma. This emotional distance explains the longstanding effects of isolation. Even after the physical isolation of patients was outlawed, patients faced stigma and loneliness in society. The perceptions the state perpetrated for the sake of control are difficult to reverse and require extensive public health campaigns, especially considering leprosy was already stigmatized to begin with.

Powerless Patients: Julia's Medical Record. Social stratification existed within isolation. Protocols were unclear, leaving patient requests for temporary releases and/or other forms of treatment at the mercy of a physician or director. I read about one particular case in a medical record held at the Emilio Ribas Museum of Public Health. Julia's medical records showed she had at first gone through domiciliary isolation. As her disease worsened, the DPL rescinded her approval for domiciliary isolation and she went to a leprosarium. Her husband, Jose, gathered documentation necessary to re-approve her for domiciliary isolation. He included a letter saying that they would live in the same previously approved house with the same people. Jose also attached a letter from a doctor assuring they would be professionally responsible for her at home medical care.

As I passed these documents in Julia's file, I saw a stapled note from a fellow patient at the leprosarium. The note from 1945 read as follows:

> "I heard here in Padre Bento sanitarium, that patient Julia, will go home, I know that there is a newborn child there, and those who will live with the diseased are healthy, because of this I also deem myself in the right to leave, to go home and care for my children, if I do this it is for the good, of that child, and the young mother, I ask this communication is kept secret, it is for the good of the sanitarian service, and justice is necessary."
>
> *"Soube aqui no sanatorio Padre Bento, que a internada Julia, vai domiciliary , sei que lá tem uma creança recen-nascida, e quem vai morar com a doente são pessoas de saude, já que é assim eu tambem mê julgo no direito de ir, para casa e tartar de meus filhos, sê faço isso é para bem, daquela creança, e a jovem mãe, peço segredo dessa comunicação, é para o bem do serviço sanitario, e é preciso haver justiça."*(1945)

The note exploits the stigma of leprosy in the name of "justice." Julia initially obtained her freedom while other patients remained isolated. These privileges distanced Julia from fellow patients, leaving her subject to isolation from her peers within the isolation of the leprosarium. The stigma propagated by the DPL is seen in the patient's written support for the "sanitarian service" and her concern for the wellbeing of the child and young mother that would supposedly be living with Julia. A letter from the DPL director Dr. Salles Gomes Junior to Jose followed the note. It stated that the request for the domiciliary isolation of Julia had been rejected.

Julia's family showed that Julia would be living in the same home that had previously been approved by the DPL under the care of a doctor assuming all responsibility for her case. The director, a man who likely never personally met Julia, declined her request. As detailed as the medical record is, it did not include the letters from local authorities that led to the denial from the distant director. Nonetheless, the case shows the vulnerability of patients to the DPL and the unclarity of criteria for ambulatory treatment. Patients were powerless in these arbitrary decisions. This powerlessness made isolation a hopeless sentence for leprosy patients. Feeling helpless, these patients suffered from low self-esteem and self-stigmatization.

Final Thoughts on Government Control. The government's power over civilian bodies fortified the already existing stigma by creating an emotional and physical separation of society and patients and by leaving patients helpless. The separation fortified public stigma, as seen with the DPL's poster. For the sake of control, the government promoted unempathetic responses to leprosy and associated leprosy with a crime. This tendency was a bureaucratic version of the biblical portrayals of leprosy as a punishment for those who sinned. The legislation was complicated, leaving patients unaware of their rights or the protocols. Physicians and directors made decisions on a case by case basis, leaving patients completely helpless when they were denied their requests. This helplessness impacted their self-view and strengthened self-stigma. In these ways, isolation worsened the social situations patients faced.

Stigma Overcomes Family: Maria's Oral Narrative

I met Maria in Santa Izabel, a leprosarium in Minas Gerais. Her narrative shows the power of stigma, particularly how it can destroy families. As seen from previous sections, the stigma of leprosy can come from biblical portrayals, the state, and/or social isolation. The powerful pubic stigma impacts people's perceptions of patients, even if they are family. Even when it did not impact the perception of the patient, isolation ended hopes of living together as a family for patients. Stigma and policy had a longstanding impact on patients, leaving many depressed or unsatisfied with their lives.

As I walked through Santa Izabel with a MORHAN representative and three other leprosy researchers, I met several patients that shared brief anecdotes that I include in this thesis.

I chose to dedicate an entire subsection to Maria's case since her experience highlights how stigma surpassed family ties and stripped patients of their roles as parents and spouses. I am able to do this because Maria volunteered more details on her journey with leprosy and isolation.

Maria is a small framed, energetic eighty-four-year-old. Throughout her narration, she emphasized that she has no resentment for anyone who treated her poorly. She believes God gave her this challenging life because He knew she could handle it. Doctors diagnosed her with leprosy when she was only twenty-one years old, around 1955. By the time of her diagnosis, doctors were prescribing Sufone treatment, a cure to leprosy. Thus, it makes sense that while I saw many disabled patients at Santa Izabel, I did not notice any signs of disability for Maria.

Leprosy as an inherent trait. When she was diagnosed, Maria lived with her husband (Ricardo) and baby at her mother's house. As soon as she was diagnosed, her mother disowned her and demanded that Maria, Ricardo and the baby moved out. Maria's mother's response to leprosy speaks to the power of the stigma and how it continued even after the disease became curable. Maria could have undergone outpatient treatment for her disease since as soon as she began Sulfone treatment, she could no longer transmit leprosy to people susceptible to the bacteria. However, outdated leprosy legislation obligates Maria to live in isolation.

Maria's mother felt the need to oust Maria from her family because of the stigma of the disease as sinful, impure, and contagious. Furthermore, her mother linked those traits to Maria's husband and daughter, disowning them by association. This account shows how the stigma of leprosy can lead to the discrimination of families, not just patients. The discrimination of the children of leprosy patients leads to intergenerational cycles of abuse and poverty. I detail the longstanding impact of stigma on the children of leprosy patients in Chapter III ("Intergenerational Effects of Isolation and Stigma: Narratives of the Children of Leprosy").

Maria’s mother considered leprosy an inherent trait, a trait integral to Mara’s identity, that reflected Maria’s personality. Based on the changing definitions of leprosy from “What is Leprosy?” in Chapter I, the mother’s perception aligned more closely with the ancient descriptions of leprosy as a spiritual disease than Dr. Hansen's biological description of leprosy as a bacterial infection. Furthermore, the state’s isolationist measures may have supported her misconceptions that leprosy was fatally contagious. The stigma was powerful and captured Maria’s mother’s attention more than the scientific evidence of a cure and bacterial transmission. This impacted both Maria and her family, completely changing her life and her daughter’s life.

Leprosy as an extrinsic trait. As per the existing legislation in 1955, Maria would still be isolated for the rest of her life. Realizing this, her husband spiraled into depression. He felt disappointed that they would not live out the marriage they had pictured. Ricardo, unfortunately, did not overcome the heartbreaking news of Maria’s isolation and committed suicide. While Maria’s mother viewed the disease as one of Maria’s inherent qualities, her husband separated Maria from her disease. Ricardo feared the government’s stigmatization of leprosy through isolationist policy more than he feared the disease itself. He showed this when he expressed his despair at the thought of living away from Maria. The state chose to continue isolationist policy at the cost of contributing to the stigma of leprosy even with a cure at hand. Ricardo, as the spouse of a leprosy patient, was a victim of this decision. The end of Maria’s relationship with her mother stemmed from her mother’s personal perceptions of leprosy, while the state’s participation in stigma ended her marriage against her and her husband’s will.

Maria attended her husband’s funeral and left her daughter, just months old, under her mother’s care. When Maria came home, she could not find her daughter. She asked her mother where the baby was. Maria recalled, her mother’s cold reply; her mother had sold the baby to some strangers she found on the street. Maria's mother stigmatized both Maria and her daughter for Maria's diagnosis. By selling her granddaughter, Maria's mother shows again how the stigma carries from the patient to those directly associated with them. The traumatic experience could further affect Maria and her daughter's mental health.

Final thoughts on stigma overcoming family. Throughout her years in isolation, Maria's mother and brothers never reached out to her. Maria, despite her disease, outlived all of her siblings. She asked for temporary releases from the leprosaria to attend each of her siblings' and mother's funerals. At the funerals, her family ignored her. Due to the stigma of leprosy, Maria lost her role as a wife, mother, sister, and daughter. The stigma affected her, the patient, and changed the lives of her husband and daughter.[6] In this section, I show two perceptions of leprosy. Maria's mother viewed leprosy as an inherent personality trait and labelled Maria an unworthy daughter and mother because of her diagnosis. Maria's huband, Ricardo, separated Maria's identity from the bacteria. His biggest struggle with the diagnosis was accepting Maria's isolation, ultimately leading to his suicide. A leprosy diagnosis affected the whole family. The family members show the different ways stigma can impact family dynamics: changing other's perceptions of the patient, leaving family members at the will of unfair legislation, and distancing children from their biological parents.

Prioritizing Empathy Instead of Stigma: Guimarães's Short Stories

About one year after Maria was isolated, in 1956, João Guimarães Rosa published his epic novel *The Devil to Pay in the Backlands* (*Grande Sertão: Veredas*) with brief but important

---

[6] After the events described above, Maria rebuilt her life in isolation and remarried. When isolation was outlawed, she adopted a son, and eventually, her and her daughter reunited. Despite the hardships she faced, she is optimistic and grateful for the family she has created post-isolation.

mentions of leprosy. João Guimarães Rosa (1908-1967) was a renowned Brazilian writer. His writing usually portrays the struggles of rural Brazilians in the twentieth century. In his writing, Guimarães humanizes marginalized groups, including leprosy patients. Despite living during isolationist policy in Brazil, Guimarães provides an empathetic portrayal of leprosy patients. Guimarães was a physician. His empathetic portrayal of leprosy may have been influenced by some clinical understanding of the existing cure. Nonetheless, his consistent empathy for stigmatized groups makes his portrayal of leprosy patients fit his repertoire.

Guimarães makes brief mentions of leprosy in some of his pieces: “The third margin of the river” (“A terceira margem do rio”) and “Substance” (“Substância”). These fleeting moments are valuable representations of leprosy and the stigma associated to it. Guimarães indirectly comments on how the stigma of leprosy compares to other stigmas. He portrays patients as victims of the disease and its stigma, deviating from the blame the biblical stigma puts on patients.Guimarães published the two short stories, “The third margin of the river” and “Substance”, in *Primeiras Estórias* in 1962. The pieces deal with themes like social acceptance, family relations, and marginalization. He portrays the lifestyles of the low-income classes throughout his work, including characters struggling with poverty and colloquial language. Since leprosy correlates with poverty, the topic comes up as he describes the typical challenges of the low-income classes.

Grouping stigmatized diseases: leprosy and mental illness. In “The third margin of the river,” the narrator describes his relationship with his father. His father abandoned the family when the narrator was still a child. The narrator claims his ashamed mother, in light of neighborhood gossip, responded “sanely.” He describes people’s assumptions as follows:

> "Our mother, ashamed, acted sanely: for that reason, everyone thought of our father a reason they did not want to speak of: insanity. Only some thought, however, that it could also be a promise payment; or that, our father, who knows, for scruple of being with some ugly disease, like leprosy, deserted himself for what seemed another existence, close and distant to his family."
>
> "*Nossa mãe, vergonhosa, se portou com muita corura; por isso, todos pensaram de nosso pai a razão em que não queriam falar: doideira. Só uns achavam o entanto de poder também ser pagamento de promessa; ou qu, nosso pai, quem sabe, por escrúpulo de estar com alguma feia doença, que seja, a lepra, se desertava para outra sina de existir, perto e longe de sua família dele.*"

The neighbor's theories include insanity and leprosy. The link between the absentee parent and leprosy through the narration of the child suggests the consequences of isolation on the children of leprosy patients. Leprosy legislation left the children of leprosy patients parentless. The fact that Guimarães mentions this shows the public was somewhat aware of this problem in the 1960s. I detail the trauma of the children of leprosy in Chapter III.

Guimarães says the neighbors assumed the father's absence was for reasons not to be spoken of and includes mental illness and leprosy. Mental illness and leprosy patients are historically stigmatized diseases. Both of these illnesses led to the isolation of patients, in psych wards and leprosaria respectively, hiding away what society deemed unpleasant. In fact, Guimarães refers to leprosy as one of the "ugly" diseases alluding to the symptoms of untreated leprosy and ignoring the impact of Sulfone treatment. The lack of dialogues on these diseases contributes to the stigma by keeping people disconnected from patients and ignorant to the true nature of the diseases.

Patient innocence. In “Substance”, Guimarães also ties the stigma of leprosy with other stigmas, but here he highlights the innocence of the patients. The anecdote speaks of the tragic family history of a servant girl hoping to be accepted into a new town:

> “Because, against the least fortunate, luck splatters black on portals and doors: a mother, light, disappeared from home; a brother, wicked, in prison, for act of death; the other, also ferocious, randomly escaped; the father, reasonable good man, betrayed with leprosy, and pursued, certainly forever, to a lazaretto.”
>
> *“Porque, contra a menos feliz, a sorte sarapintara de preto portais e portas: a mãe, leviana, desaparacido de casa; um irmão, perverso, na cadeia, por atos de morte; o outro, igual feroz, foragido, ao acaso de nenhuma; o pai, razóavel bom-homem, delatado com a lepra, e prosseguido, decerto para sempre, para um lazareto”*

Guimarães makes a distinction between the father’s identity and his affliction. He claims the father, a “reasonable and good man”, was “betrayed” by leprosy. He juxtaposes the father’s leprosy with the other family member’s fatal flaws: a mother who abandoned her children and murderous brothers. The awful acts of the mother and brothers highlight the father’s innocence. Both leprosy patients and criminals face stigma, but Guimarães makes it a point to show how unjustifiable the stigma of leprosy is by comparing it to that of assassination and child abandonment.

Final thoughts on prioritizing empathy. Guimarães shows empathy for leprosy patients while reflecting on the negative consequences of stigma on families. In fact, in *The Devil to Pay in the Backlands,* the narrator says of Só Candelário, a leprosy patient:

> “Now, that I think, of all the people Só Candelário is the one I most understand.”
>
> “Hoje, que penso, de todas pessoas Só Candelário é o que mais entendo.” (340)

The narrator's relationship with Só Candelário shows leprosy patients as human, appealing to empathy. This is the exact opposite of the portrayal we saw earlier in the DPL's poster. Furthermore, Guimarães establishes associations between stigmatized diseases, particularly mental illness and leprosy. His critique of these stigmas separates the diseases from the individuals and suggests that the grouping of disease with other sins is illogical. He makes a statement about stigma and disease in general, taking blame away from patients. His portrayals of leprosy, although brief, provide us with the perception of leprosy patients as people who had the poor luck of getting the disease at no one's fault. Unfortunately, this awareness of the disease and the impact of stigma on patients is still uncommon even half a century later.

Conclusions

Isolation legalized and encouraged the discrimination of leprosy patients. The physical deformities that accompanied the disease subjected leprosy patients to immediate discrimination. Gonçalves's poems discuss themes of physical scarring, self-stigmatization, and solitude. The government kept patients emotionally and physically distant from the rest of society. The separation of families had longstanding effects for Gonçalves, Maria, and many of the patients that lived in leprosaria. Patients felt helpless and powerless under the inconsistent, seemingly arbitrary decisions of state representatives. Overall, isolation had traumatic effects that are yet to be overcome in some respects. Leprosy became a hidden disease, leaving the public ignorant to its minor symptoms and treatment today. Without any direct contact with patients to counter the misinformation, many people in Brazil still believe the disease is severely contagious and incurable, and thus, continue to discriminate patients out of fear of contagion. Guimarães showed an empathetic approach to leprosy which showed the human side of patients rather than the diseased side. This philosophy should be generally adopted, especially now that leprosy is curable. Unfortunately, isolated patients continue to suffer the traumas of the leprosaria and new patients hide their diagnosis to avoid discrimination because of the stigma of leprosy.

Chapter III: Post-Isolation (1976-2018) Traumas and the Burden of Hiding Leprosy

This chapter will highlight the continuity of stigma after the outlawing of compulsory isolation. I will analyze the intergenerational impact of isolation through narratives of the leprosy patients' children to show how the stigma impacted them and had longstanding effects on their lives. I use Veganin's painting *Via Sacra* to show the patient perspective on leprosy and isolation after being granted the liberty to leave. My interviews from 2017 and 2018 to show how the stigma of leprosy manifests itself in the twenty-first century and the forces that act to reinforce it post-isolation. The chapter suggests that the stigma of leprosy must be addressed socially, legally, and artistically. Since the stigma exists in different mediums, it must also be mitigated legally, culturally, and socially.

In 1976, Federal Ordinance No. 165/BSB outlawed compulsory isolation of leprosy patients in Brazil. While the ordinance was an essential step for the rights of leprosy patients, it neither resolved the trauma patients and their families suffered nor changed the public perception of leprosy. Moreover, The Movement of Reintegration of People Impacted by Hansen's Disease (MORHAN) highlights that even though isolation was illegal, the state continued to isolate patients in leprosaria until 1986("Deputados aprovam pensão a portadores de hanseníase isolados até 1986," 2011). I struggled to find the precise date when isolation ended because of the disconnect between legislation and reality. I chose to use 1976 to demark isolation because the ordinance marks the beginning of a transition to patients' rights.

Patients gained the right to leave leprosaria when isolation ended, yet some had nowhere else to go. Some lived a large portion of their lives inside the leprosarium. They befriended and married other leprosy patients. Outside of the leprosaria, they struggled to find employment and housing because of the stigma. Thus, leprosaria still house patients, and I was able to interact with several of them at Santa Isabel and Pirapitingui.

MORHAN began in 1981(Morhan, 2011b). This non-profit organization advocates for the rights of leprosy patients, particularly those who suffered isolation. In 1995, under MORHAN's insistence, the Brazilian government approved Federal Law No. 9.010, mandating the use of "Hansen's disease" instead of "leprosy" on all official documents in an attempt to avoid the stigma linked to "leprosy"(Opromalla, 2011). The transition to "Hansen's disease" helped ameliorate the immediate impact of the diagnosis by changing the terminology to one without the heavy connotations of "leprosy". However, the change has also left the public ignorant to the clinical progress made in treating leprosy since all of the posters only address "Hansen's disease." When some people realize that "Hansen's disease" and "leprosy" are synonymous, they apply their misconceptions of leprosy to Hansen's disease and discriminate patients. I explicitly use the term "leprosy" in this project to directly address misconceptions of the disease and reveal the abuses those misconceptions have led to. My goal is to help mitigate the stigma of leprosy, instead of shielding it with different terminology.

MORHAN spearheaded the fight for government reparations for patients who suffered isolation, which became law in 2007 with Federal Law No. 11.520 (Morhan, 2011a). They continue to advocate for leprosy patients by releasing video campaigns against stigma, conducting primary-school leprosy education programs, and legally seeking reparations for the children of leprosy patients removed from their parents in isolation (explained further in this chapter). Despite MORHAN's extensive efforts and changes in legislation, patients still suffer discrimination, abuse, and trauma from the stigma of leprosy.

This chapter uses oral narratives primarily to see the stigma of leprosy post-isolationist policy. I was unable to find any literary portrayals of leprosy for the period, but I do include one painting and one public health TV ad in my analysis. Since this chapter is based on more recent years (1976-2018), I was able to gather more accounts from patients and their families. This allows me to analyze patient experiences directly. These narratives proved valuable to my overall analysis of the power of stigma and its impact on patients and clinical care.

Intergenerational Effects of Isolation and Stigma: Children of Leprosy's Narratives

MORHAN estimates that about 16,000 children were separated from their parents during isolation (1923-1976). MORHAN calls the removal of leprosy patient's children a "state crime" and "the biggest case in history of parental alienation done by the Brazilian state" in their twenty-minute documentary *Children Separated by Injustice* published on Youtube in 2017. According to a patient's narrative in the documentary, the nurses would immediately take the babies away to be washed elsewhere. The mothers were not allowed to hold their babies or see their child before the nurses took them away. The babies were then transported to orphanages. Mothers told me directly and mentioned in the documentary that after some months, personnel at the leprosarium would tell them their children had died in the orphanage. The mothers today are confident these notices were lies meant to keep them from searching for their children. Separation traumatized both patients and their children; the victims of separation deal with the psychological consequences of this experience long after the outlawing of isolation. In this section, I combine narratives I gathered with narratives from a MORHAN documentary to analyze the intergenerational effects of the stigma of leprosy. I specifically focus on the themes of trauma and inescapable poverty to develop my analysis.

I met three children of leprosy patients that suffered the trauma of being separated from their parents. They all mentioned employees in the orphanages labelling their belongings to keep them separated from the children unrelated to leprosy patients. The employees would keep their things separate from those of the rest of the children to avoid contagion of leprosy. “But we never had leprosy,” they told me. The children of leprosy patients carried the stigma of leprosy via their association with their parents. Employees mocked them calling them “lepers” even though they never had leprosy themselves. The stigma of the disease affected them as well as their parents.

The stigma made the children undesirable in the adoption system. In fact, the federal Ministry of Health released a public health poster in 1950 attempting to promote the adoption of those children. The poster reads, “Leprosy is not hereditary. The children of leprosy patients are perfectly healthy children” (See Appendix L). The children of leprosy patients were rarely adopted and some of the narratives I gathered tell of being adopted into “slavery”.

The combination of family separation and stigma had grave consequences on the children of leprosy patients. I address the ways the stigma of leprosy reaped psychological and financial repercussions for the children of leprosy and how isolation provoked a chain of trauma and marginalization for generations to come. The children of leprosy patients are rarely researched, and their stories have hardly been documented. This section only begins to fill that void and allow them to voice their traumas. Further research is needed to address this community’s needs and to thoroughly document their lives to avoid future family separations.

The experiences of the children of leprosy in the adoption system differ from that of other orphans in that the state deemed their parents unfit because of a disease, leprosy. The state’s separation of leprosy patients and their children was a direct cause of the abuse and trauma the children suffered. The psychological and physical abuse could have otherwise been prevented if the children would have resided with their biological parents. Moreover, the children faced verbal abuse in the orphanages related to the stigma of leprosy despite never having the disease themselves. They were well aware that their parents had leprosy for this reason and were treated like contagious vectors for the disease with their few belongings labelled and separated from the rest. These acts of discrimination added an extra layer of abuse and trauma to their childhoods.

Physical abuse and disability. The state justified family separation as a prophylactic measure to prevent the children from contracting leprosy. Ironically, the extensive physical abuse many of the children faced in the orphanages or in their adoptive families left them physically disabled. One interviewee in the documentary mentioned being hit until his ears bled. Another was beat with a paddle until the paddle snapped. These speakers go on to describe the physical disabilities they face as adults (blindness, difficulty walking, body aches) from the physical abuse they suffered as children.

The body mutilation did not necessarily end when families adopted them. During my visit to Santa Isabel, I met Inês, a woman now in her sixties who was born in Santa Isabel (Minas Gerais), sent to an orphanage, and returned to Santa Isabel as an adult in search of her biological parents. While the parents had passed away, Inês managed to track down where they had been isolated. Ines told me of her tense relationship with her adoptive family, which she described as "slavery." She claimed the family adopted her for the sole purpose of cleaning the house and cooking. Her adoptive parents constantly beat her. Consequently, she wears a brace on her leg and uses a cane to walk. She consistently clarifies to visitors that her brace and cane are not from leprosy since she never had leprosy but from the physical abuse she suffered in her adoptive family. The clarification shows her need to distance her identity from the disease so that others do not discriminate her.

Inês's narrative and that of some interviewees in the documentary specify physical consequences of isolation and the stigma of leprosy. The physical disabilities from the abuse they suffered as children are irreversible. The state claimed to place the children in the adoption system to avoid leprosy's physical consequences, but the adoption system caused Inês and others physical disabilities from the beatings in the orphanages and in their adoptive families. The scarring of their bodies, although unlinked to leprosy, can lead to marginalization via stigmas of disability in general. Thus, family separation negatively impacted the physical health and bodies of leprosy patient's sons and daughters. The scars traumatized the children and made them vulnerable to social isolation, taking a toll on their mental health as well.

Psychological abuse and irreparable trauma. The children of leprosy patients suffer from mental illness because of the many psychological traumas they faced. In the MORHAN documentary, a victim said, "Almost all of the sons and daughters [of leprosy patients] have mental illness." Employees of the orphanages would use leprosy stereotypes to verbally abuse the children by calling them "lepers" as mentioned earlier. The abusers took advantage of the children's vulnerability and used their parents' disease in their abuse. The use of leprosy to abuse the children shows the power of the stigma of leprosy. Even though they never had leprosy, they were mistreated because they were associated with leprosy. Leprosy made them vulnerable to psychological abuse particularly linked to the stigma of leprosy, unlike the other children of the orphanages.

I met Sofia in Santa Isabel. I gathered her narrative through her sister, Joana, since Sofia suffers from severe mental illness and cannot talk. Sofia is in her late fifties. I had the privilege of hearing Sofia sing, her only form of communication. She specifically sings songs she remembers from her time in the orphanage. According to Joana, Sofia was traumatized when she was taken to the orphanage. Her longing for her parents made her cry often to which employees at the orphanage responded to by medicating her. They medicated Sofia to the point where she was sedated. Sofia was so over-medicated as a child that today her brain is not fully functional. She suffers from severe mental illness that make her dependent on her sister and MORHAN's financial and legal help. Sofia's over medication show the lack of empathy and proper care the children received in the orphanages. This led to psychological repercussions that, for Sofia, are irreparable. Mental illness is also a stigmatized disease. Thus, the vicious chain of unsound prophylactic measures, abuse, illness, and stigma continue.

I met Joana when I visited Santa Isabel, and she appeared in MORHAN's documentary. She was also born to leprosy patients. She spoke of the sexual, physical, and psychological abuse she suffered as a child in the documentary. She specifically mentioned receiving a doll, her prized possession, in the orphanage. Every so often she would feel sad and miss her parents. One time, an employee of the orphanage responded by taking Joana's doll and "cutting the dolls fingers and feet," saying "When you are thinking of your mother, look at your doll." (MORHAN).

The mutilation of Joana's doll was an act of abuse with the purpose of emotionally distancing Joana from her mother. In order to create this emotional distance, the abuser used unpleasant leprosy symptoms to create a negative image of Joana's mother. The abuser portrayed the Joana's mother as a diseased body rather than a suffering human being. This dehumanization fortifies stigma. The employees attempt to make Joana harbor disgust for her mother was unsuccessful. The event did, however, leave a psychological mark on Joana, and she recalls the anecdote with tears in the documentary. The trauma has repercussions on the mental health of the children of leprosy. Furthermore, it distances them emotionally from the rest of society. This distance is a form of psychological isolation that separates those associated with leprosy from the rest of society. Consequently, the stigma remains unacknowledged by those unaffected by leprosy and those affected are left to suffer alone.

Inescapable poverty. When I spoke with Joana, she shared that she ran away at sixteen to escape her abusers. She was young and homeless, but even in that desperate situation, she refused to return. Without many options, she became a sex worker to make a living. Tears streamed down Joana's face as she told me she had only two dreams in life. First, she hopes to find her other sister, which the state took from her mother in Santa Isabel. Second, she longs for a decent job where she can "earn her money respectably." "That's all I want," she said. Her humble goals speak of the lack of options for marginalized classes. Impoverished conditions can lead to more disease, creating a vicious cycle.

Other children had similar anecdotes of homelessness and poverty as they tried to escape the adoption system. Many children of leprosy patients continue to struggle to find employment. Mental and physical disabilities diminish their chances of finding jobs. In addition, one of MORHAN's interviewees in the documentary cited "lack of education" in the orphanages in the documentary as a barrier to employment. These challenges leave the children of leprosy stuck in a low socioeconomic status. The inescapable poverty can drive them to drug addiction, crime, and prostitution and lead to more disease. The lack of social mobility affects their families, including their children as well, creating a chain reaction that proves difficult to stop.

Final thoughts on intergenerational effects. In the MORHAN documentary, children of leprosy patients compared orphanages to "hell," "slavery," and prisons. One man said, "Prisoners in jail lived better than a person that was admitted into an orphanage." Both employees and adoptive families physically, mentally, and sexually abused children of leprosy patients. They took advantage of leprosy's stigma to further hurt the children. A combination of being separated from their parents, discrimination within the adoption system for leprosy, and the many types of abuses common to orphanages created particularly traumatic experiences for the children of leprosy patients. Survivors continue to face the scars of these traumas, hoping that MORHAN will obtain financial reparations from the federal government. The financial reparations would help them since they are unable to obtain jobs because of the series of disabilities onset by their families' separations and the discriminations they face for being associated to disability and/or leprosy.

Biblical Stigma After 1976: Veganin's Painting and the Pope's Misuse of "Leprosy"

Patient art (such as that in Chapter 1) and provides a narrative for the experience of leprosy. From 1944 to 1981, patients were cured with sulfone treatment, the first cure to leprosy (See "What is Leprosy?"). Sulfone treatment had painful side effects. Multidrug therapy became the standard treatment for leprosy in 1981, a cocktail of antibiotics with significantly less side effects. Veganin lived during the sulfone era. His painting, *Via Sacra*, develops the ancient and biblical stigmas of leprosy, pointing specifically to condemnation and patient experiences in the Santa Isabel leprosarium (See Appendix M). The theme of condemnation and biblical stigma is further developed in speeches by Pope Francis. I separate my analysis into two subsections: "Veganin's Painting" and "The Pope's Speeches." Both sections touch on different perspectives of leprosy as a biblical condemnation: one of a patient battling for his health and the other a Catholic interpretation of biblical readings.

Veganin's Painting. Luiz Carlos de Souza (1950-1997) lived during the sulfone era. He suffered intense pain during his treatment in Santa Isabel, one of the two leprosaria I visited. There he painted *Via Sacra*, a painting that allows us to understand the burden of leprosy during the transition period from isolation to non-isolation and the damage that remained after isolation had been outlawed. I will use Nadja Cristiane Lapann Boti and Kiane Aparecida Aquino's article for the biographical information on the artist (Boti, 2008).

Luiz Carlos de Souza began working at the age of sixteen as a volunteer at the Holy House of Mercy Infirmary in Belo Horizonte, Minas Gerais. While working at the infirmary four years later, a physician diagnosed him with leprosy and referred him to Colonia Santa Isabel, the leprosarium where I conducted ethnographic research in Minas Gerais. According to Boti and Aquino, he did not have any contact with his family after his diagnosis since his family members that letters from him would transmit the leprosy. In Santa Isabel, he became known as "Veganin." As a nurse, Veganin would abuse of a medication by the same name relieve his pain He also provided the medicine for others in the infirmary of Santa Isabel. Hence, he was nicknamed for the medication. Boti and Aquino highlight that this an example of the loss of identity in leprosaria. Patients lose ties to their previous life; in Luiz Carlos de Souza's case, this included changing his name.

Veganin enjoyed soccer, movies, books, cartoons, and painting during his free time. Nonetheless, he consistently refused to accept the title of "artist." The Saint Bernadinus College[7] in Holland sponsored Veganin's *Via Sacra*, a series of fourteen rectangular 84x 60 cm paintings that are today in the church of Santa Isabel. He worked on the paintings from 1987 to 1992.

---

[7] Boti and Aquino do not specify exactly how the Saint Bernadinus College found Veganin. They do note that the ex-parish priest of Santa Isabel was Dutch but do not explain if there was any direct contact between the priest and the Saint Bernadinus College in Holland.

According to Boti and Aquino's calculations, Veganin was paid 99.46 times the minimum wage at the time for his work. Of the fourteen paintings, I focus specifically on the fifth in the series, where he depicts Simon of Cyrene carrying Jesus's cross. He incorporates themes of his own life by setting the painting in Santa Isabel and including symbols of leprosy throughout. He particularly develops the theme of condemnation and includes patients and healthcare providers as characters in *Via Sacra* to elaborate his struggles as a leprosy patient in the late twentieth century.

Condemnation: allusions to biblical and ancient leprosy. Simon of Cyrene is in the center of the painting towering over the other characters. Biblically, the Romans encouraged Simon of Cyrene to carry Jesus's cross to the crucifixion. In the painting, he carries a cross filled with a crutch, a scalpel, a prosthetic, pills, a hospital bed, and a syringe among other medical materials. Veganin is showing the leprosy patients condemnation to medication. At the time, physicians would cure patients using sulfone treatment. While this antibiotic would cure patients, it would have painful side effects. Veganin suffered these side effects, and thus, depicts this experience in the cross. At a lack of staff in the clinics, directors at the leprosaria would force patients to work certain jobs, including caring for other patients. Boti and Aquino analyze, "o próprio tratamento da hanseníase se tornou a cruz para o hanseniano." The placement of this image at the center of the painting and the magnitude of the cross which comes off the borders puts health as the principal ideal for leprosy patients. It shows patients' longing for the healthy life they previously had before they were isolated, discriminated against, and in pain.

Veganin further develops the theme of condemnation through the direction of Simon's treck. He is walking towards Santa Isabel's gates. Once officers took patients to leprosaria, they were condemned to a lifelong sentence within those walls. Even after the government outlawed isolation, patients stayed. After years of living there and being out of contact with their families, patients built new lives within the leprosaria's gates. When they were finally given the freedom they desired, they had nowhere else to go. Veganin uses trauma as a strong criticism of isolationist policy, expressing the longstanding effects isolation had on patients.

Veganin also includes ancient symbols like the Captioline Wolf, Trojan Horse and a man in a Roman outfit. These ancient depictions parallel the ancient discrimination of leprosy patients. The man faces Simon of Cyrene and points towards the gate. The man's stance suggests that going towards Santa Isabel is an order, which it was for many patients during isolation. Interestingly, the same man that is ordering the isolation shows symptoms of leprosy. He is missing his hands. This can be representative of self-stigmatization and the social hierarchy that existed within the leprosaria.

Depictions of patients and healthcare providers. Veganin incorporates leprosy symptoms again in a female character with crippled hands. The position of her fingers is a stereotypical symptom of leprosy. Her body makes the shape of a cross, as if she too is condemned. She faces away from the viewer so that her face is concealed. This position strips her of her human identity and limits her to her symptoms. Veganin uses this depiction to critique the social isolation of patients. In the painting, the leprosy patients' identity revolves around their disease. The man in Roman dress, Simon of Cyrene and the woman differ in many aspects (size, clothing, and time period for example), but they still have the common burden of visually-distinguishable leprosy. Within leprosaria, every patient experienced leprosy. Although they came from different backgrounds and arrived in different decades, they all had leprosy in common. Within the gates, many patients lost their identities to the disease. Boti and Aquino mention in their analysis, "A história revela que a hanseníase produz perda física e social, mas como visto, também de identidade." Patient loss of identity makes the effects of stigma outlast the isolationist decrees. Recovering an identity outside of leprosy is challenging, especially when the world outside of the leprosaria is still unaware that the patients are cured and not contagious.

Veganin also includes the people who helped patients in the leprosaria as characters in his painting. In the bottom left corner, there is a man in a white coat with a doctor's bag. This man is the physician helping to cure the patients. Beside him, there is a nurse dressed completely in white. Veganin's inclusion of these two characters shows appreciation for their services to leprosy patients. While I visited leprosaria, I noticed that patients were very appreciative of anyone who took interest in what had happened to them. The stigma of leprosy leaves patients helpless and alone. Moreover, the disease was hidden by the government and is now actively hidden by doctors and patients. Thus, like Veganin, the patients I met seemed to enjoy having someone to talk to about leprosy.

Final thoughts on Veganin's painting. Veganin uses a biblical depiction to communicate his struggles as a leprosy patient in the late twentieth century. Through his depiction he criticizes the condemnation of innocent, suffering people to isolation, he expresses the difficulties of returning to a healthy state, and he expresses gratitude for the service of those who helped patients.

The Pope's speeches. The theme of religious condemnation of leprosy patients has continued for centuries. Pope Francis began his papacy in 2013. He continues to use leprosy as an example of sin in speeches. MORHAN has successfully reached out to Pope Francis to express concern for stigmatizing discourse on leprosy. Nonetheless, the Pope does not distinguish between biblical leprosy and modern leprosy, reinforcing misconceptions of the disease as sinful, contagious, and incurable.

In 2013 at a meeting, Pope Francis linked condemned behaviors with leprosy; he said:

> May the Lord give to all of us the courage to strip ourselves of the spirit of the world, not of 20 lire, but the spirit of the world, which is the leprosy, the cancer of society! It is the cancer of God's revelation! The spirit of the world is the enemy of Jesus! I ask the Lord that, he give us all this grace to strip ourselves. Thank you! (Francis, 2013a)

Pope Francis associated leprosy with "cancer" and the "enemy of Jesus" in his statement. The false equivalency of leprosy and cancer can have repercussions on patient care by increasing patient avoidance and delayed diagnosis (See "What is Leprosy?"). In associating leprosy with cancer, the Pope implies that leprosy is a fatal and hopeless disease when in reality, leprosy is curable. This can harbor fear in patients that begin to see symptoms and thus, lead to patient avoidance and delayed diagnosis. Furthermore, it reinforces the ancient depictions of leprosy rather than fostering an accurate image of leprosy today. This address was not the only occasion in which Pope Francis spoke of leprosy contemptuously. In an address to the Community of the Pontifical Ecclesiastical Academy in 2013, he said "Careerism is a form of leprosy, a leprosy. No careerism, please" (Francis, 2013b).

During my time in Santa Isabel, I met Thiago Flores, a MORHAN representative that met with Pope Francis to explain the consequences of the Vatican's negative discourse on leprosy. According to Thiago, the Pope promised to make an effort to encourage empathy for leprosy patients rather than condemnation in the Catholic church. Soon after the meeting in 2015, the Pope had a holy mass focusing on leprosy in the Bible with an empathetic rhetoric. He highlighted the extensive social and physical suffering of leprosy patients saying,

> Imagine how much suffering and shame lepers must have felt: physically, socially, psychologically and spiritually! They are not only victims of disease, but they feel guilty

> about it, punished for their sins! Theirs is a living death; they are like someone whose father has spit in his face (cf. *Num* 12:14).
>
> In addition, lepers inspire fear, contempt and loathing, and so they are abandoned by their families, shunned by other persons, cast out by society. Indeed, society rejects them and forces them to live apart from the healthy. It excludes them. So much so that if a healthy person approached a leper, he would be punished severely, and often be treated as a leper himself. (Francis, 2015)

Francis emphasized the many consequences of a leprosy diagnosis, citing physical, social, psychological, and spiritual isolation. He directly mentioned family abandonment which was particularly evident in Maria's oral narrative (Chapter 1). The Pope empathized with leprosy patient's suffering in the 2015 address, a seemingly pivotal moment for the many Catholic leprosy patients in Brazil. This conscientious attitude, however was short lived. In a prayer at the Colosseum in 2018, the Pope said "you alone can heal us from our leprosy of hate, selfishness, pride, greed, vengeance, avarice, idolatry; you alone can embrace us again, restoring our filial dignity and rejoicing in our return to home, to life" (Francis, 2018). Thus, the church continues to contribute to the stigma of leprosy by linking the disease to sin and patients, regardless of their religious denomination, continue to face biblical stigma.

Final thoughts on biblical stigma. In communicating his suffering, Veganin calls for empathy. The painting shows the suffering of patients and attempts to appeal to people's empathy instead of fear. Human portrayals of leprosy patients are essential in the process of de-stigmatization; the public begins to see patients as people and not vectors of disease through art. Art can impact the common discourse on leprosy, educating its audiences on the consequences of stigma and modern leprosy. The Pope has consistently linked leprosy to religious and societal condemnation. Veganin develops this theme as well, pointing specifically to his suffering in Santa Isabel. The Pope, however, continues to portray biblical leprosy without distinguishing it from today's leprosy, a curable disease. Small efforts have been made to change the religious discourse of leprosy like the brief changes in Pope Francis's attitude towards leprosy in 2015, but these changes have been inconsistent. The stereotypes and stigma of leprosy are bad habits that have proven difficult to break. The cultural references in movies and art to leprosy as a crippling, deadling disease are brief but consistent, making it difficult for society to eliminate the stigma.

Hiding Unpleasant Symptoms: Clara and Fernanda's Narratives

This section focuses on modern-day patient's plight to conceal their leprosy symptoms. I begin by detailing hospital procedures for leprosy. I then use two narratives to establish my analysis on hiding unpleasant symptoms. I specifically focus on two patients that were unable to conceal their symptoms. Clara faced a severe case of leprosy. Her unpleasant symptoms left her quarantined from the rest of the hospital so other patients would not be disturbed. Fernanda fell victim to poor medical care. She arrived with a severely distorted foot, a disability that would have been preventable with proper antibiotic treatment. Her narrative shows the consequences of misdiagnosis and mistreatment of leprosy. Both Clara and Fernanda could not uphold their confidentiality because of their symptoms. Efforts must be made to train physicians so that they diagnose leprosy promptly and treat it appropriately. Furthermore, general education on leprosy symptoms and transmission would help prevent the mistreatment of patients with higher grades of disability.

Observing Hospital Procedures. In 2018, I spent one week observing doctor's appointments at the Eduardo de Menezes Infectiology Hospital in Belo Horizonte, Minas Gerais. Primary-care physicians throughout the state refer patients to this hospital for treatment of advanced infectious diseases that local clinics are ill-equipped to treat. During my ten weeks in São Paulo I only saw two cases of leprosy; in this specialized infectiology center, I saw sixteen cases in just one week. I use what I witnessed throughout the week to explain the protocols physicians follow to treat patients.

I do not mention every single patient specifically since at times patients did not mention stigma, discrimination, or suffering. This may be because it simply did not come up in conversation with their physician. Varying degrees of comfort at the doctor can affect a patient's dialogue with their doctor. It may also be that they have not suffered discrimination either because their community was particularly accepting of leprosy or because the patient managed to conceal their symptoms. Patients' experiences differ. Public health research is needed to identify what factors specifically relate to discrimination. I focus on the narratives that mentioned instances of stigma, since these offer me the opportunity to discuss the stigma of leprosy today. The fact that there were any patients facing discrimination because of their diagnosis is unjustifiable. Public health officials, the federal government, non-profit organization, and healthcare workers should make an effort to eliminate the stigma of leprosy.

The upcoming subsections detail the procedures patient's follow upon arrival in the hospital. I separated procedures into steps: "Check-in," "The physical therapist and disability," "The physician's role," and "Contact cases." These sections are meant to clarify clinical care for leprosy in Brazil today, particularly for special cases with symptom complications.

Check-in. The Eduardo de Menezes Infectology Hospital provides both out-patient and in-patient care. I spent most of my time working with the dermatology unit, since they receive the leprosy cases. Upon arrival, the patient checks in at the front desk. The receptionist then refers leprosy patients to a small building next to the hospital, the physical therapy unit. I was surprised that patients prone to disability would be forced to walk elsewhere, across a dirt road, to be examined and then forced to walk back to the dermatology unit. The hospital is meant to treat complicated cases of leprosy, which usually suffer visual disability and/or physical disability. The infrastructure seemed illogical since it increased the patient's physical burden of going to the doctor and put the patient at risk of further injury.

Physical therapist and disability. The physical therapist performs tests to examine the patient's touch sensitivity, eye-sight, and reflexes. They use a series of monofilaments, thin sticks with differing thicknesses, to poke the patients toes and fingers while their eyes are closed. The therapist progressively increases the thickness of the monofilaments until the patient identifies when they feel the poke. They fill out a state-mandated diagram detailing which areas have lost the most sensitivity (See Appendix N). The therapist tests the blinking reflex since leprosy affects ocular nerves that signal the person to blink. These tests indicate the patient's level of disability (See "What is Leprosy?" in Chapter 1 for further details on disability). Insensitivity means that patients do not feel things touching their hands and feet. Thus, they do not feel pain when they hurt themselves. I was only able to see one physical therapist test for disability. I have since asked infectologists in the United States, and the procedures seem customary for the treatment of leprosy. The procedures also fit the standards of the government-provided forms for leprosy (See Appendix N).

During a consult, I met Luis, a middle-aged man who worked in construction. He recalled an object falling on his foot at work. He said "Naturally, I removed it off my foot and continued with my day." Eventually, he looked down and realized he had unknowingly bled through his shoe. Patients often fail to notice smaller cuts and wounds because of their leprosy disability and those small injuries can lead to fatal infections. I consistently heard the physical therapist advise the patients to wear closed- toed shoes to protect against any hits. She also warned against wearing flip flops, since patients with high disability often lose their flip flops without realizing and continue walking barefoot on the streets. Disability is completely preventable with medication, but delays in diagnosis can lead to insensitivity, mainly in the hands and feet. The physical therapist documents the patient's disability, gives suggestions on how to prevent disability, and then sends the patient with his/her chart back to the waiting area in the main building.

The physician's role. The patient returns his clinical file to the receptionist and takes a seat in the waiting room. The receptionists place the charts in a pile by the consult rooms. Each doctor goes to the table and grabs the next file as they finish appointments. I would flip through the pile and look for the leprosy cases. As the doctors came to the table and picked up a leprosy file, I would follow them. The doctors would explain that I was a student from the United States observing leprosy appointments for the week. They would then ask the patient if they were okay with me observing their appointment. Since a team of doctors would grab from the pile of medical records, I observed three different doctors treating leprosy.

The doctors first looked at the physical therapist's notes and often adjusted dosages accordingly. They asked if they had any symptoms and if any new scars had appeared since the last consult. On rare occasions where the patient had severe symptoms, the physician would hospitalize them for in-patient care. This was the general procedure I saw, but there are of course exceptions.

Contact cases. Contact cases are carried out differently. When patients are first diagnosed, the state expects them to report all the people they live with and have consistent, daily contact with. Leprosy is rarely contagious with only 5 percent of the population susceptible to the bacterium. It also requires daily, consistent contact with an untreated patient for over six months for a person to get leprosy. Leprosy is rarely contagious because of the extensive contact and the rare susceptibility to the disease. When there are contact cases however, they often occur within the same household. This may be because of similar living conditions and/or because of a genetic component to bacterial resistance. The state requires patients to notify their families to avoid disability and diagnose patients early on[8]. The hospital reaches out to the people patients report to see if cohabitants are infected.

During my stay, a mother diagnosed with leprosy brought in her son to be checked. He had a small blemish on his back. The dermatologists determined the blemish was unrelated to leprosy. This case did not undergo the typical procedures, since the child did not arrive seeking leprosy treatment. The case did show me the difficulties of diagnosing leprosy since the dermatologists based themselves off of the appearance of blemishes rather than bacterial cultures. Diagnosing leprosy is particularly difficulty because the bacteria does not survive outside of the body, making positive skin smears confirming the diagnosis rare. As a consequence, patients are often misdiagnosed and only begin treatment when the disease has progressed to disability. While shadowing at the hospital, I witnessed a variety of cases. Some cases with little to no severity, like the negative contact cases, and some particularly severe cases of leprosy, like Clara whose case is detailed in the next paragraph. The range of patient experiences allowed me to see the different approaches physicians take to treat leprosy in Brazil today and the ways stigma plays a role in different degrees of leprosy.

---

[8] Note: Once a patient is diagnosed and begins treatment, they no longer spread the bacteria. Therefore, the state does not take these measures because they fear a recently diagnosed patient will continue to spread the disease, but rather because there may be other members of the househould that have leprosy but are yet to notice their symptoms.

Symptoms lead to isolation: Clara's narrative. One of the residents took me to meet Clara, a middle-aged woman with Lucio's Phenomenon, a rare extreme case of leprosy found almost exclusively in Mexico and Central America (Herath, 2015). With Lucio's, the patient's immune system does not respond to the bacteria and allows it to grow completely uninhibited, leading to severe symptoms rapidly (Herath, 2015). Clara was in the last room of the corridor. She suffered necrosis, rotting of the flesh, throughout her right leg from the knee down. The necrosis filled the room with a pungent smell. While other patients were in shared rooms, Clara was separate. The physicians had initially placed her in rooms with HIV/AIDs patients, indicating that the doctors did not isolate her for fear of contagion. The resident doctor later explained to me that Clara was in a separate room because other patients could not stand her odor. Physicians attempted several room transfers, but the other patients consistently complained, resulting in Clara's isolation.

The psychological and spatial isolation Clara faced was different from that discussed in the previous chapter in that it was not legally imposed, nor did it restrict her from seeing her family. In fact, when I visited Clara, her son was there making sure she was bathed and cared for. While there were differences with the leprosaria, Clara's isolation in the hospital yielded similar results. The physical isolation of placing Clara in a separate room leads to mental isolation because she was unable to engage with other patients. Mental isolation is the tragic result of physical isolation as we saw in the previous chapter on isolationist legislation. Clara was hidden in the corner room of the hospital, directly preventing her from interacting with others. Society's lack of interaction with leprosy patients maintains ancient perceptions of the disease and dehumanizes the patients. Increased interaction can help spread awareness at a personal level and allow others to learn that leprosy is not contagious by experience.

Clara is a contemporary example of exclusion on the basis of symptoms that are socially unacceptable. Her odor prevented her from sharing her patient experiences in the hospital with others. She was excluded from the typical interactions among patients and was not given the opportunity to share her story in the hospital. The "talking cure" takes into account the therapeutic effects of talking about experiences (Marx, Benecke, & Gumz, 2017). Whether the "talking cure" is the most effective form of therapy is up for debate, but Clara was not given the opportunity to decide for herself whether sharing her experience would help or not. Furthermore, the lack of interaction with Clara leaves other patients unaware of her situation or her lack of contagion. Some patients may have incorrectly assumed she was quarantined because of a contagious disease, but certainly, none of the patients were able to witness the treatment of leprosy, its symptoms, and the human experience of the disease.

Preventable disability and stigma: Fernanda's narrative. I remember the moment Fernanda walked into the hospital. She was struggling to take every step with her walking cane. Her ankle was completely bandaged, but from the shape the bandages took, I could immediately tell she had severe disfigurations. Her foot twisted off to the side, making her stand on the side of her foot instead of the bottom. The physical therapist had not been able to perform her monofilament test for disability because of the extent of the disfiguration. The dermatologist brought her in, and the residents all quickly gathered to watch the unique case.

The physician immediately called in the orthopedic specialist. The specialist watched Fernanda take a couple of steps and then went with the doctors and me to another room to look at the X-rays while nurses removed the bandages to get a better look at the wound. The doctors knew it was a case of osteomyelitis, infection of the bone. Osteomyelitis is a serious risk for leprosy patients. Since leprosy patients often hurt themselves without noticing because their nerves are compromised, they are susceptible to infections from other bacteria. Hence, patients should be monitored consistently for symptoms of infection in their hands and feet.

As they looked at the X-rays, the orthopedic specialist repeated "What am I supposed to do with that? What could I possibly do?" Fernanda's bone had been eaten away. When they removed the bandages, a large, deep wound on her ankle was revealed. The doctors brace themselves to tell Fernanda she would have to lose her foot. Meanwhile, Fernanda secretly hoped they would remove her foot. Her foot had become a painful burden. It had to be rebandaged several times a day. It impeded her from walking without help. Most importantly, her foot had become the focal point of her identity. As soon as she walked into the waiting room, others noticed her disfigured foot. When the doctor came to explain his decision, Fernanda asked him to please amputate before he could mention it. She simply could no longer withstand the pain and discomfort it was causing her. Clinically, the doctor knew the infection posed serious health risks for the future. They scheduled her surgery for the upcoming weeks.

The doctors were visibly frustrated by Fernanda's case because amputation is preventable. In 2016, the WHO set the goal of less than one newly diagnosed leprosy patients with visible deformities per million population by 2020. In a research project I conducted with Dr. Jessica Fairley in Rollins School of Public Health and I used the Minas Gerais State Department of Public Health to identify trends in grade 2 disability. We found that although the incidence of leprosy is decreasing, the rate of grade 2 disability has increased since 2002 with a 16 percent rate of grade 2 disability among new cases in 2016. The high rate of grade 2 disability suggests that there are large delays in diagnosis. Many physicians are unaware of the symptoms of leprosy and the proper methods of treatment and disability prevention. This leads to misdiagnosis and progression of the disease to degrees that could have easily been prevented with antibiotics.

Final thoughts on hiding symptoms. Disability makes leprosy unconcealable, leaving patients vulnerable to stigma and discrimination. Like with Clara, Fernanda's symptoms were extremely apparent and socially unpleasant to witness. Preventing the disease from reaching this stage, through early diagnosis and treatment, could help patients avoid stigma by keeping their disease private. This, however, cannot be the only measure taken. The stigma associated with disability shows a need for government funding of public health campaigns. Public health campaigns advocating for the end of discrimination can help mitigate prejudices in tandem to clinical disease treatment and disability prevention.

During the week in Belo Horizonte, I was exposed to an environment where cases are seen on a daily basis. I experienced the clinical aspect of leprosy in Brazil, and I met several patients. Shadowing at the hospital allowed to understand how doctors diagnose and treat leprosy today, and while doing that, I reflected on reasons why the stigma of leprosy persists even in 2018. Through Clara, I noticed that patients remained separated from the rest of society because of their symptoms, reinforcing misconceptions of contagion. Through Fernanda, I realized the need for educating physicians on leprosy to prevent the physical and social toll that comes with disability. Even with a cure in hand, society fails to accept patients suffering leprosy's most unpleasant symptoms.

Battling Widespread Misinformation: Guilherme, Tiago, and Ana's Narratives

The main challenge in combating the stigma of leprosy is the widespread ignorance of the disease. People still believe the disease is dangerous and contagious even though scientists have proven otherwise. This misinformation occurs across social strata and all throughout the world. Without proper knowledge of leprosy, misconceived stereotypes and fear persists.

Misinformation among professionals. While observing at the Eduardo de Menezes Hospital, I met Guilherme, a patient that had been referred to the hospital by his primary-care physician. The dermatologist asked what he had been feeling that he was sent to this hospital, distant from his home. The patient explained he had symptoms of a cold earlier on, but he had since gotten better. The doctor went on to ask for symptoms of leprosy, "Any blemishes? Nerve insensitivity?" to which Guilherme said no. Guilherme's primary care physician referred him to the hospital because of his history with leprosy although he had no symptoms related to leprosy. This shows the inability of the physician to identify whether the case should or should not be referred to a leprosy specialist. The physician was unaware of the symptoms of leprosy. This misinformation was inconvenient for Guilherme, which had to miss work and go to the hospital just to be told that he had no reason to be there.

Physician misinformation did not have a drastic, long term impact in Guilherme's case. Clara's case was an example of the clinical impact physician misinformation can have; clinically, the patient faces more severe symptoms because of delays in diagnosis. Misinformation can also have a psychological impact. The physical therapist at the hospital told me of Tiago's experience at the dentist. She claimed Tiago struggled with molar pain and waited to get an appointment with the dentist. When he went to the dentist, he filled out his chart as per usual, describing his medical history including his ongoing treatment for leprosy. When the dentist saw Tiago had leprosy, the dentist refused to help him and demanded he never come back to his office. According to the physical therapist, Tiago went home and ripped out his tooth himself. The dentist's ignorance left Tiago helpless. Despite the professional's higher education, he still feared leprosy and could not overcome his misconceptions. The dentist then engaged in acts of stigma, diminishing Tiago to a tainted person because of one attribute. This left Tiago helpless and alone facing his pain.

Misinformation in families. While in São Paulo, a physician specialized in state-monitored diseases told me of Ana's case. She had diagnosed Ana just the day before. She described it as a particularly sensitive case because Ana was only sixteen years old. Pediatric cases of leprosy are rare because of the long incubation period of the disease. Ana's symptoms began with blemishes on her face. She used to live with her alcoholic mother who had leprosy. Ana was certain that her mother did not follow treatment as directed. She had detailed this history years ago when she arrived in São Paulo. She moved to São Paulo to live with her aunt and younger cousins. She spent two years being diagnosed with "dermatitis" before she was finally correctly diagnosed with leprosy. According to her physician, she expressed aesthetic concerns, saying she would be "ugly" and scarred, but Ana's physician noted that her main concern was her aunt's response to her diagnosis. Ana feared that her aunt would no longer allow her to live in her home with her younger cousins. The doctor explained that she would come in with her family for a slide show where she would explain that the disease is not contagious and answer any questions they may have. Although I do not know how Ana's family actually responded to her disease, Ana's fear of rejection indicates the presence of stigma and the emotional toll stigma can take on patients.

Final thoughts on misinformation. This fear of rejection can impact patient care and cause delays in diagnosis. Henry *et. al* from the Lauro de Souza Lima Institute, a dermatology institute specialized in leprosy, conducted research on delays in diagnosis (Henry et al., 2016). They categorized delays into patient delays and health system delays. Unsurprisingly, the main health system delay was misdiagnosis. The main patient delay was fear of isolation. This delay then leads to the onset of severe disabilities and thus, more susceptibility to stigma as discussed in the previous section. Patient delays and health system delays must be addressed in order to avoid disability and thus limit the stigma patients face. Clinicians must be trained to recognize leprosy symptoms and the general public must be educated on their rights as patients and leprosy's curability.

Poverty Begets Poverty: Diogo and Pedro's Narrative

In the first chapter, I noted the demographics of leprosy, particularly that the disease disproportionately affects impoverished populations. It is likely that poor living conditions leave patients vulnerable to the bacteria. Most of the patients I saw at the hospital worked physically grueling jobs, mainly in construction. As disability increases, these jobs become more difficult to sustain. Symptoms and stigma can leave patients unemployed or homeless. Thus, a vicious cycle ensues where poverty leads to disease which then leads to more poverty. I gathered two narratives that exemplify how stigma can affect patient livelihood.

Loss and self-defense: Diogo's narrative. I walked into what people commonly refer to as a favela in São Paulo with a community agent from the local primary care clinic[9]. As we entered through the dirt path, some of my stereotypes were debunked. I realized that favelas are not just housing complexes; this favela had a daycare, a restaurant, and a salon. The living conditions were poor overall, but even within the poverty, there were social classes. There was a

---

[9] The Brazilian Ministry of Health's website explains what is expected of a community agent. A community agent "deve visitar regularmente residências e fazer registros da população, em relação a documentos básicos para o acesso aos serviços de saúde e em relação aos possíveis problemas de saúde que possam ser identificados na residência"(Ministério da Saúde, 2019). The community agent facilitates access to healthcare by easing communication between households and medical teams.

family that lived in a shack the size of a closet. The walls were thin pieces of cardboard and there was no flooring. Other families lived in apartment buildings with brick walls and electricity (although the electricity was often turned off during the day to save money). Originally, the visit was meant to show me how community agents help the marginalized populations in Brazil. The experience was supposed to be completely unrelated to my research on leprosy. As we walked, the community agent introduced me to several of her patients and explained that she served as a mediator between the physician and his patients by communicating patients' needs and updating the physician on patients' health.

She eventually asked me about my research. I explained my project had to do with leprosy, and she immediately recalled Diogo, a leprosy patient. She took me to Diogo's home to introduce me. Diogo, a man in his seventies, opened the door in his wheelchair. I recognized a couple of scars from leprosy when I saw him but what stood out the most was the absence of his leg. He welcomed me and the community agent into his home. The living room was dark because there was no electricity, but even through the dim lighting, I could see many pictures of his family on the walls. I sat on the couch facing Diogo in his wheelchair as he told me his story.

He never told me the exact year the doctor had diagnosed him, but he mentioned he was living in rural Minas Gerais. He had to travel to see a doctor. He said the doctor ran "some tests" on him, and then Diogo went to his apartment to await the results. The results arrived in a letter. Diogo's landlord received the letter in Diogo's name and opened it. When Diogo returned from work, the landlord greeted him with an eviction notice. Diogo recalled him saying "You are a leper. You cannot live here." Diogo skipped ahead to when he decided to move to São Paulo because there was more access to leprosy medication. He pointed out that the disease had left some marks on his face and arms but made it a point to clarify that his missing leg was from a motorcycle accident and not from leprosy. He followed by saying that no one in his family but him and his sister had leprosy.

The landlord's harsh decision to evict Diogo was an act of prejudice. The stigma of leprosy continues in part because a majority of the public is unaware that leprosy is curable and not highly contagious. Fear then takes precedent over empathy. Diogo's example shows the need for more effective health communications and health education. While the government publishes brochures and posters on "Hansen's disease", many people do not connect Hansen's to leprosy, leaving their beliefs on leprosy unaddressed. This ignorance then maintains a popular fear of contagion which encourages the continuity of stigma.

Diogo felt the need to clarify his symptoms and the lack of contagion. In pointing out that his amputation had been for reasons other than leprosy, Diogo attempted to project an image of his health unrelated to leprosy. According to him, he had leprosy but only with minor symptoms, showing a concern for the perception of his symptoms. He felt the need to justify himself even as he talked with us, people working directly in healthcare. He realized that he could not hide the scars he had accumulated throughout his life and that those scars could lead to misinterpretations of his health. His experiences as a leprosy patient have fostered defense mechanisms against stigma such as clarifying what symptoms are from leprosy. These interactions can help diminish stigma and misconceptions by clarifying what the disease looks like. It is concerning, however, that patients employ these defenses and potentially feel they have no peer to communicate with when they are feeling unwell.

Diogo indicated the rarity of contagion by specifying that no one in his family had leprosy besides him and his sister. This shows Diogo's awareness of the public fear of contagion. His response to this fear was speaking about his experience with leprosy. Some leprosy patients consistently justify themselves to others in attempt to qualm others' fears and therefore not be discriminated against. This creates a larger emotional separation between society and the patient, leaving the patient psychologically isolated. I imagine Diogo does not share these stories with everyone to avoid the stigma and to distance his identity from leprosy. When we prompted him to talk about his "experience with leprosy," he specifically detailed the discrimination he had suffered, his symptoms, and low contagion. This showed his fear of other people's perceptions. The patients' fears as well as the public's fears distance the patients and inspire "othering." Since the population of patients facing leprosy is a small minority, these patients can feel alone facing their disease. Stigma is both fear-driven and fear-inducing. The public must be made aware that their fear is unfounded, and patients should be provided safe environments to share their experiences, giving the public exposure to what it is like to live with leprosy today.

Patients in hiding: Pedro's narrative. One afternoon at the Eduardo Menezes Hospital, I sat with the physical therapist, Armanda, in her office after her last patient. I explained that I was doing research on the stigma of leprosy and that I was visiting to understand how leprosy is treated today. Armanda replied with a patient's story. Pedro was diagnosed at the hospital. He kept his diagnosis a secret from everyone but his family. "You know that is what doctors always advise the patients," Armanda explained. Pedro lived in a favela. One night, he began to feel unwell for reasons unrelated to leprosy. The family had to call an ambulance. Pedro went to the hospital and made a full recovery, but in the midst of the chaos between an unwell Pedro and the ambulance, Pedro's secret became neighborhood gossip. When Pedro returned from the hospital, he found someone had burned his house down.

As described in a previous section ("Hiding Unpleasant Symptoms: Clara and Fernanda's Narratives"), patients face the challenge of keeping their diagnosis confidential. Physical symptoms can reveal the diagnosis as we saw with Diogo, Clara, and Fernanda, but the diagnosis can also be revealed in different ways as with the case of the dentist or in Pedro's case. Without an environment where they can openly speak of their disease, patients are forced to try to conceal their diagnosis. Keeping it a secret can make patients feel like they are hiding a fatal flaw, making them self-conscious. Doctors advise patients to hide their leprosy for the patient's safety, but sometimes keeping it hidden is not under their control. When their secret is unveiled, patients can feel even more helpless; not only could they not help getting the disease, but they also failed to be the narrators of their stories as leprosy patients. This helplessness decreases patients' self-esteem. Measures need to be taken to inform others that it is perfectly safe to interact with a leprosy patient. Once a safe environment exists for patients, patient should be encouraged to share their stories to humanize the disease and appeal to people's empathy, making it clear that leprosy today can be inconsequential with proper treatment.

Final thoughts poverty begets poverty. Both Diogo and Pedro were living in impoverished conditions and facing leprosy. When others found out about their condition, they were stripped of their houses. This is reminiscent of the isolationist period (1924 to 1976), when political elites created policies that robbed patients of their homes. The forces acting on Diogo and Pedro are different in that they are individuals instead of the Brazilian government. Nonetheless, the end results for the patients are similar in several ways: lower self-esteem, emotional isolation, and a loss of their homes.

Conclusions

Despite the outlawing of isolation, the stigma of leprosy still affects patients' quality of life. The children of isolated leprosy patients continue to face the consequences of isolationist policies today. They face the trauma of being separated from their parents and abused in orphanages. Furthermore, mental illness and physical disability from those abuses has left them with no opportunity to escape poverty. Although they never had leprosy, they are victims of the stigma of leprosy. The children of leprosy are an example of the intergenerational, longstanding effects of stigma. MORHAN seeks government reparations for these citizens as well as elimination of patient discrimination.

Today, some physicians attempt to minimize discrimination by asking patients to hide their symptoms. Unfortunately, symptoms can become unconcealable and leave them vulnerable to mistreatment as with Clara and Fernanda. When others realize traces of disease, they can choose to distance themselves from leprosy patients, leaving the patient marginalized as was the case before 1976. Others can also engage in acts of violence and prejudice against patients, subjecting already impoverished patients to increased poverty. These discriminatory acts decrease patient self-esteem and prevent patients from sharing their experiences with leprosy. This leaves others with ancient perceptions of leprosy, ignorant to modern-day treatment and its minor symptoms. This creates a vicious cycle of discrimination, ignorance, and stigma. Furthermore, the lack of knowledge of minor leprosy symptoms can lead to delays in diagnosis because the patient fails to recognize the importance of seeing a physician for a small, insensitive blemish.

Although policies have changed, efforts are needed to aid the children of leprosy and to revert the misconceptions the government indirectly reinforced by isolation patients. Efforts should consist of public health campaigns (posters, TV advertisements, brochures). The Brazilian government has already attempted to help by designing posters and brochures. In 2018, the Brazilian Ministry of Health ran the campaign “Hansen’s Disease. Identified. Treated. Cured.”(Ministério de Saúde). The cover on the webpage for the campaign featured a smiling man hugging his son followed by explanations of the disease. The titles of the subsections were "What is it?," "Symptoms," "Transmission," and "Treatment and Cure." This portion of the campaign lacked visual aids for illiterate populations. Since leprosy affects a high number of illiterate patients (See "What is leprosy?" in Chapter II), it is of utmost important to effectively communicate symptoms and curability to people who were not taught to read. At the bottom of the page, there was a video ad titled "Combat Hansen's Disease." The video ad could help communicate essential points to illiterates and briefly depicts leprosy symptoms. These ads, however, do not seem to be reaching intended audiences since the stigma and misconceptions still exist. Further research is needed to identify how to reach a broader audience with these campaigns and effectively communicate key points.

Despite doing research on this topic, I never saw a poster nor a video ad about leprosy during my time in Brazil, which begs the question. Where are these campaigns posted? Who is their audience? While I commend the small steps by the government, posters need to be more visible and communicative to both a literate and an illiterate audience. This thesis shows that the sources of stigma vary, including paintings and literature. Creators must be made aware of their misconceptions of leprosy through public health campaigns. As the public consumes paintings, novels, and films, false metaphors and allusions to biblical leprosy reinforce the stigma on the rare occasions where leprosy does appear. Otherwise, leprosy is unmentioned, leaving the public with outdated perceptions. Since the stigma was reinforced from all angles, it must be mitigated through efforts from all angles as well.

Conclusions

In general, stigma leads to the exclusion of certain populations from society, and therefore, creates a barrier to the exchange of ideas and experiences. Inclusion can foster new perspectives on discriminatory issues plaguing society. Within the context of leprosy in Brazil, my research indicates that dialogues with leprosy patients would encourage new approaches to health, inclusive of biological and sociological factors. Taking into account socioeconomic status, living conditions, and discrimination against patients would improve clinical care in general, including for HIV, cancer, mental illness, and leprosy patients. This improvement in clinical care would help decrease disease rates among low-income classes, potentially decreasing the stigma of poverty. Leprosy patients experience the intersection of multiple stigmas; diseases, poverty, disability, and race. Diminishing one of the stigmas and encouraging empathy can directly affect the other stigmas by challenging unfounded beliefs based on stereotypes. Although race and poverty are related to disease, I focus on understandingthe continuity of the the stigma of leprosy despite shifts in politics, medical advances, and legislation in Brazil. Leprosy stigma continues to affect both patients and a broader population whose social actions often give the impression that leprosy knowledge is widespread.

My multidisciplinary analysis shows that the stigma of leprosy continued to exist and led to similar repercussions for patients and their families between 1923 and 2018 and that ideas of leprosy stem from several sources (religion, art, literature, memory of earlier cases of leprosy). Discrimination of leprosy patients can take a toll on their well-being and quality of life, affecting clinical care. While some people do not know leprosy still exists, they do retain cultural beliefs of leprosy inconsistent with the clinical definition of leprosy as a curable infection.

Leprosy poses challenges to researchers making policy proposals. On the one hand, the clinical disease is not widespread, even though in Brazil its incidence is the second highest in the world. On the other hand, my research demonstrated stigma means that the public, whether medical professionals or not, have preconceived notions about leprosy, rarely based on actual contact with those who have or have had the disease. Sociocultural definitions of leprosy as a punishment for sin and a contagious, disfiguring disease are more widespread and do not align with the clinical definition of leprosy today. The fear of leprosy, as defined culturally, then drives a sociological separation between leprosy patients and the public long after physical isolation.

People's continued association of leprosy with biblical or ancient portrayals indicates a lack of awareness of leprosy as a bacterial disease unrelated to patients' characters. Brocos's engraving (1920s), Gonçalves's poetry (1930s and 1940s), Maria's narrative (1955), Veganin's painting (1987), and the Pope's speeches (2013 and 2018) allude to condemnation and sin in their accounts of leprosy. The patient recounts of biblical stigma show the traumatic effects it can have on patients and their families, and the deep and long-term way it continues to create negative cultural associations in society broadly. Differentiations when referring to biblical leprosy and leprosy today may help create distinctions and establish the public's association between today's leprosy and the existing cure.

Another common theme in my sources was family separation and the impact of disease on family dynamics. The topic appeared in Gonçalves's poetry (1930s and 1940s), Julia's medical record (1945), Maria's narrative (1955), Guimarães's short stories (1962), the children of leprosy's narratives (1970s to 2018), and Ana's narrative (2017). Family separation greatly impacted leprosy patients. Research on Latin -American and African refugees in Canada has suggested that trauma and family separation can have a significant impact on emotional distress (Rousseau, 2001). Similarly, the sources in this thesis show that the traumas of isolation and disease combined with separation from families created a particularly distressful experience for patients and their families. This distress affected both the patients of leprosy and the generations to come, leaving longstanding effects. The children of leprosy patients continue to struggle financially from the mental illness and disability caused by abuse in their childhoods. Furthermore, some families engaged in interpersonal stigma and alienated their loved ones because of their diagnosis. Maria's mother disowned her and sold her child because of her interpretation of leprosy as an inherent character flaw. Ana's narrative was a contemporary take on family and leprosy. She feared her family would abandon her. These fears paralleled Maria's experience. Ana's fear shows a need for a holistic approach to patient care that takes into account the physiological symptoms of leprosy and the disease's social and psychological repercussions.

The physiological symptoms of leprosy that left patients vulnerable to discrimination were apparent in several sources. In Brocos's engraving (1920s), I showed how the symptoms were indicative of low-income classes and how stereotypes helped justify isolation decrees as a humanitarian effort. Gonçalves's poetry (1930s ad 1940s) and Veganin's painting (1987) similarly show the diagnosis of leprosy as a condemnation. Both depict the symptoms of leprosy in their works from first-hand experiences in the leprosaria and highlight lifelong scarring from the disease. When I spoke with Diogo (2017), he strived to distance himself from his symptoms and distinguish unrelated scars from those of leprosy. His experiences with leprosy drove him to proactively downplay his symptoms to avoid discrimination. Clara and Fernanda's narratives (2018) both provided examples of unpleasant symptoms of leprosy that were readily identifiable by others and left them socially isolated. Across the many sources described in this paragraph, physiological symptoms impacted patient interactions with others and with themselves, lowering their self-esteem and quality of life. Despite the outlawing of compulsory isolation, unpleasant symptoms can still lead to the spatial and psychological isolation of patients, reaping harsh consequences on patient's overall wellbeing.

A final theme throughout the sources is poverty. In Chapter I, I established the correlation between poverty and leprosy worldwide and within Brazil. Indirectly, patient biographies and oral narratives in the sections show poverty as an agent in disease manifestation. I specifically address the correlation of poverty and leprosy in Brocos's engraving (1920s), the narratives of the children of leprosy (1970s to 2018), and Diogo and Pedro's narratives (2018). Disease and poverty are a vicious cycle where poverty leads to disease which leads to more poverty and therefore more disease. In addition to this vicious cycle, leprosy's stigma can leave patients marginalized, disabled, and unemployed, further perpetrating the inescapable cycle. Furthermore, the low-income population tends to work physically demanding jobs. Minor injuries are common while working these occupations but pose serious consequences for leprosy patients. Insensitivity makes it difficult for patients to notice these injuries and leaving them untreated can cause fatal infections and therefore, disability. Disability can then increase the likelihood of discrimination and unemployment. This creates a particularly challenging cycle for leprosy patients, leaving them vulnerable to disease and stigma.

Compulsory isolation was a form of institutional stigma. This stigma and legislation persisted until 1976, separating families and traumatizing patients. Moreover, the institutional stigma of legislation worsened existing self-stigmatization of patients and interpersonal stigma from others. The consequences of leprosy isolation are still faced today. Government agencies must create public health campaigns to target the diverse origins of the stigma of leprosy:

religion, professionals, patients' families, pop culture, art, and literature. Combatting the stigma of leprosy would lead patients to obtain an early diagnosis, decreasing the likelihood of disability, and lessening the consequences of the disease. In my next section, I summarize my specific recommendations for policy and initiatives that would help patients based on my research.

Recommendations

The overwhelming stigma leprosy patients face today suggests a need for efforts to (1) diminish disability among patients and (2) educate the general public. Decreasing rates of disability among new cases would help patients maintain their diagnosis confidential, leaving them less vulnerable to discrimination. Educating the general public would alter perceptions of leprosy, decrease fear of contagion, and increase the rates of early diagnosis. Early diagnoses are less likely to lead to disability. Thus, educating the general public can play an indirect role in diminishing disability among patients. I first propose changes the governemnt should make to public health campaigns. I then recommend that the church alter its terminology. I identify programs MORHAN could expand to new audiences. Lastly, I state my recommendations for healthcare workers.

In 1995, Federal Law No. 9.010 called for the use of "Hansen's disease" instead of "leprosy" in all official documents. MORHAN strongly supported this decision as a measure to circumvent the stigma linked to leprosy. The shift to Hansen's disease may have helped patients hide their disease by giving the disease a label unrelated to the heavy connotations of leprosy. However, this transition has also created a gap in the public's knowledge of leprosy. Since all public health campaigns and research uses "Hansen's disease," I suspect the public fails to link the medical advances of multidrug therapy with leprosy. Therefore, "leprosy" has not been addressed directly in public health campaigns or research, maintaining antiquated perceptions of the leprosy. Furthermore, the stigma of leprosy limits patient interaction with others. Without personal narratives, research, or public health campaigns altering perceptions of leprosy, the public receives cultural definitions of leprosy from stigmatizing portrayals in the bible, literature, art, and cinema. Using "leprosy" in official documents would help the public acquire a more accurate definition of leprosy as curable. Further research would help identify whether using "leprosy" instead of "Hansen's disease" would provide more memorable campaigns and be more effective in changing public perception, but I hypothesize that the use of "Hansen's disease" has actually contributed, contrary to its intended purpose, to the continuity of the stigma of leprosy. Replacing "leprosy" with another term, therefore, maintains an anachronistic perspective disease.

The Brazilian government should increase the funding of public health campaigns with a particular emphasis on television advertisements and posters, since these visual portrayals of leprosy will help target illiterate populations. Visual aids will help reach at risk populations since a majority of leprosy patients are illiterate. In addition, these campaigns would provide a clear image of symptoms. This would help people identify their symptoms earlier and seek treatment prior to the onset of disability while also exposing the public to non-stigmatizing images of leprosy with minor, more common symptoms.

MORHAN should expand its educational activities in elementary schools and attempt to target art programs and writing workshops. Educating artists on the stigma of leprosy may discourage them from using stigmatizing portray or inspire them to craft artistic representations of leprosy that call for empathy instead of discrimination. Long-term, this would help change the cultural context of leprosy in Brazil. Targeting artists would encourage them to reflect on their representations of disease in general, indirectly aiding patients of other stigmatized diseases as well.

My project dedicated a section to the Pope's reinforcement of ancient perceptions of leprosy. I acknowledge that several religious texts directly reference leprosy. It is unrealistic to expect church leaders to completely cease to mention leprosy. I recommend that church leaders actively distinguish between today's leprosy and ancient leprosy in their speeches. This would help the public recognize essential differences between modern leprosy and leprosy prior to antibiotics. This would help diminish the church's role in perpetuating the stigma of leprosy today while still referencing the disease in religious texts.

A joint effort should be made by federal regulations and medical schools to train physicians to identify leprosy symptoms, properly treat leprosy or refer patients to specialists, and empathetically provide resources to deal with stigma and discrimination. The high rates of grade two disability in Brazil indicate a need for clinical care improvement. Henry's survey of 122 leprosy patients in Brazil in 2016 showed that 42.6 percent of participants were initially misdiagnosed with something other than leprosy (Henry et al., 2016). This shows a lack of knowledge of early symptoms of leprosy among healthcare providers. While many people (physicians and the general public) readily identify symptoms of advanced leprosy (disability, disfiguration, amputation), they are unaware of the early dermatological symptoms of a blemish insensitive to touch. Education emphasizing the initial symptoms of leprosy and increasing physicians' suspicion of leprosy as a diagnosis would encourage physicians to further examine patients and provide an earlier diagnosis. This is particularly important for physicians serving underprivileged populations. Earlier diagnoses prevent disability and allow patients to keep their disease confidential by keeping their symptoms manageable. This would help prevent discrimination since others would be unable to identify the patient's disease.

In addition, healthcare for leprosy patients should entail counseling on how to cope with discrimination. Pedro's narrative shows the limitations of patient confidentiality. Pedro managed to keep his diagnosis a secret until he had to call an ambulance for symptoms unrelated to leprosy. Neighborhood gossip spread the news of diagnosis. He returned to find his house had been burned down. His neighbors found out about his disease unexpectedly despite efforts to conceal it. In this sense, this project teaches us important lessons about the limitations of confidentiality in healthcare. In addition to patients ike Pedro, counseling would particularly help patients who have apparent disability because of leprosy. Coping resources would help avoid long-term trauma and allow physicians to have a holistic approach to the health of their patients, addressing both the biological effects of disease and sociocultural consequences of leprosy.

All of these efforts strive to educate the public on leprosy's curability and symptoms to prevent the discrimination of patients and to increase the rates of early diagnosis. They target the stigma at different angles by educating different populations. Ultimately, large amounts of funding would be needed to completely end the stigma of leprosy, but any single measure would help if it reaches the intended audiences.

Future directions

In order to improve public health campaigns and methods to end the stigma of leprosy, more funding must be allocated to research on leprosy. Leprosy could be eliminated with stronger research initiatives efforts and increased efforts for disease prevention and treatment. As

I developed my thesis, I found several gaps in knowledge on leprosy in Brazil. I now identify research areas that would help reduce the burden of leprosy.

Very few researchers have directly analyzed leprosy legislation in Brazil or provided comparison between the legislation of different states. Scholars should analyze shifts in legislation and monitoring of leprosy. Further analysis is needed of medical records that provide detail accounts of the existing protocol at the time and the gaps in regulation. This research would help identify inconsistencies in the treatment of leprosy during isolation, potential abuses of power, and characterize public health and physician attitudes towards leprosy throughout the twentieth century. The results of these projects would help us understand power dynamics between policy, physicians, and patients and prevent future abuses of power in disease legislation.

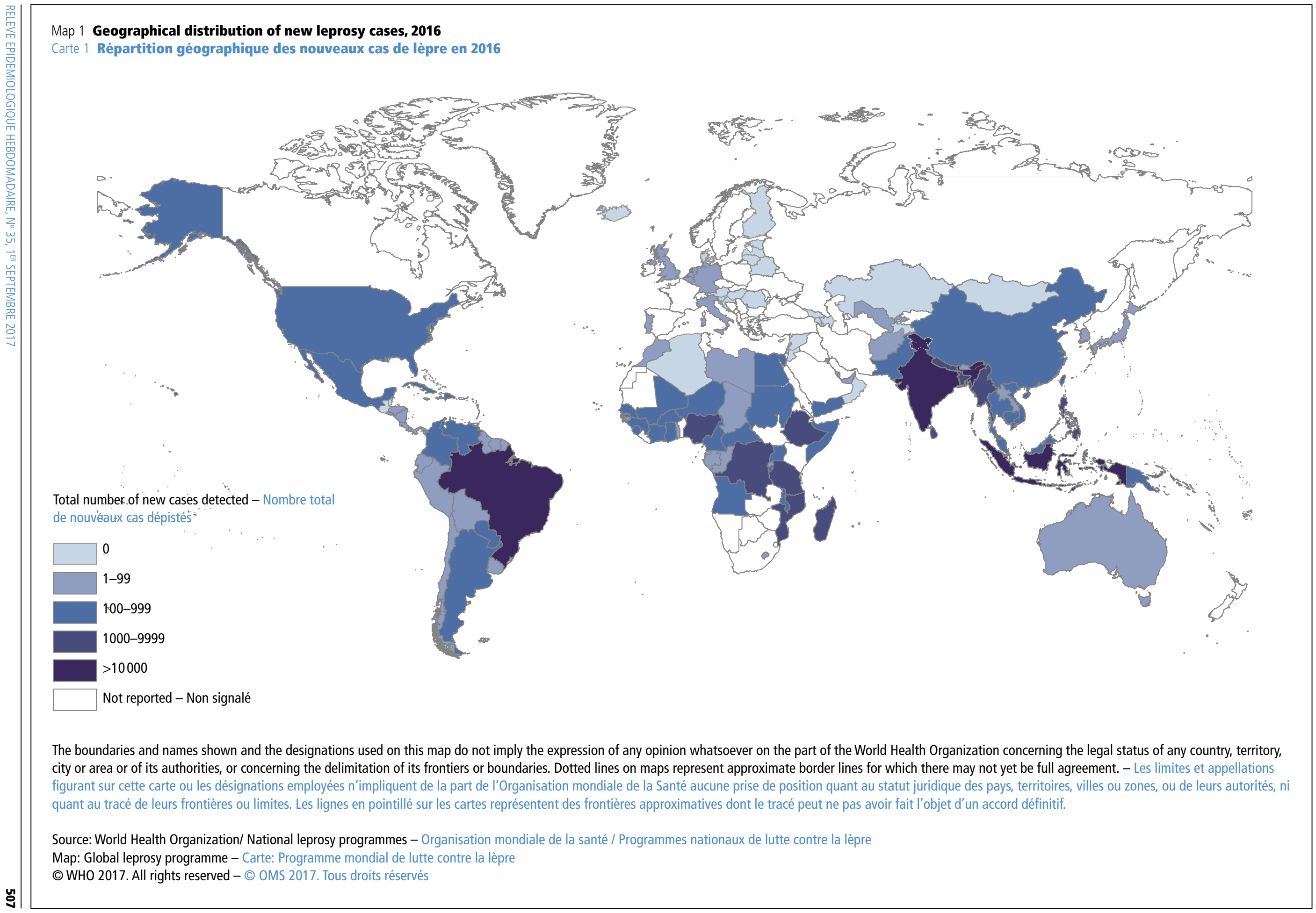
Future research should document the experience of the children of leprosy and compare the stigma and discriminations they faced due to leprosy with that of their parents. This may help address misconceptions of the disease and assist MORHAN by identifying the needs of this population. Research should also be conducted to identify why exactly patients chose to continue to live in the leprosaria post-isolation, whether they are satisfied with that decision, and what would help improve these patients' quality of life in the leprosaria today. Answering these questions would help improve the care provided for these patients and identify needs for transitions from in-patient to out-patient care. These two projects would help characterize the decisions, needs, and trauma of patients that suffered isolation and their families.

In addition to filling these knowledge gaps, research should be done to identify location and dissemination of materials, the targeted audiences, and the limitations of these methods. This will help identify in what ways campaigns have been ineffective in spreading awareness and in what ways they have been effective. I suspect illiterate populations are not being reached by the current campaigns because current brochures and pamphlets require reading skills. Several trials of different campaign strategies should be tested to optimize appeal to the public and the divulgation of leprosy awareness. This research would greatly improve public health campaigns and lead to more effective allocation of the government's and MORHAN's funding.

Research is needed to substantiate my hypothesis that "leprosy" would be more effective than "Hansen's disease" in campaigns. Surveys would help identify whether this transition has truly helped patients by comparing the beliefs of "Hansen's disease" and "leprosy." In tandem with the research on public health campaigns, researchers could test what terminology is most effective and is more memorable for viewers. Intentional research addressing the dynamics between the two terms would provide evidence supporting changes in current legislations requiring the use of "Hansen's disease."

Clinical research should aim to further identify correlations between leprosy, stigma, discrimination, and mental illness. Some of the questions in need of answers are: How often do leprosy patients today face stigma and/or discrimination? How do they define stigma/discrimination? How many leprosy patients have had the onset of mental illnesses after a leprosy diagnosis? Answering these questions will help the medical community better understand the relationships between stigma and health. It will also help identify the gravity of the stigma of leprosy faced today and its correlation with other stigmas. The research would further explain the vicious cycle between disease, stigma, and poverty. Understanding these concepts will help improve the clinical care of patients, identify sources of stigma, and address the needs of patients facing discrimination. In addition, similar research should be done with other stigmatized diseases (e.g. HIV/AIDS, mental illness, sexually-transmitted diseases) for comparative purposes. This would allow for improvements for those populations and comparisons between disease stigma. Identifying commonalities and effective methods to combat disease stigmas can aid in preventing future stigmatization of diseases through prophylactic efforts.

Appendix A: Geographical distribution of new leprosy cases in 2016



RELEVE EPIDEMIOLOGIQUE HEBDOMADAIRE, N° 35, 1er SEPTEMBRE 2017

Map 1 **Geographical distribution of new leprosy cases, 2016**
Carte 1 **Répartition géographique des nouveaux cas de lèpre en 2016**

Total number of new cases detected – Nombre total de nouveaux cas dépistés

- 0
- 1–99
- 100–999
- 1000–9999
- >10 000
- Not reported – Non signalé

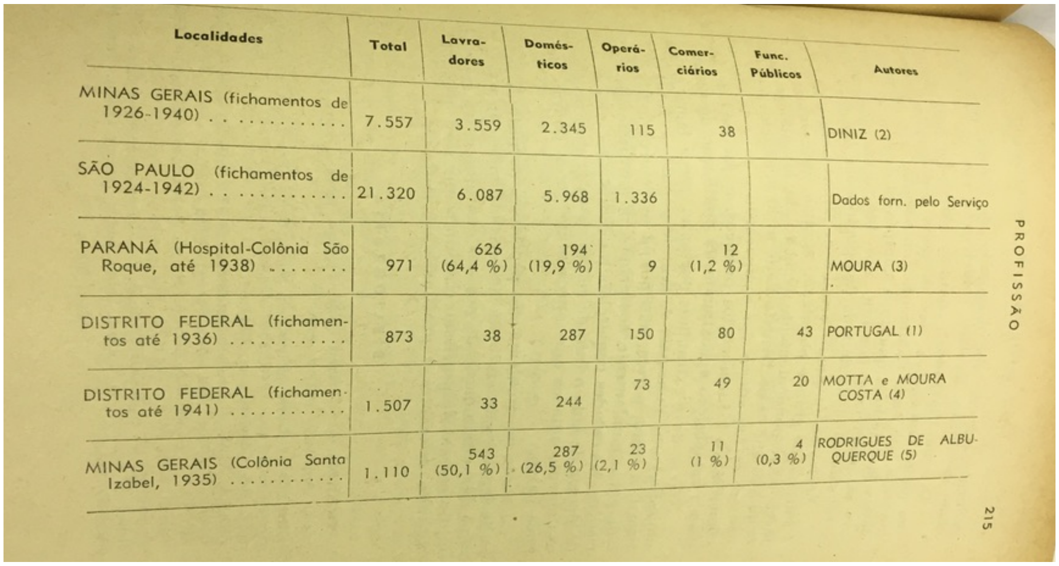
The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement. – Les limites et appellations figurant sur cette carte ou les désignations employées n'impliquent de la part de l'Organisation mondiale de la Santé aucune prise de position quant au statut juridique des pays, territoires, villes ou zones, ou de leurs autorités, ni quant au tracé de leurs frontières ou limites. Les lignes en pointillé sur les cartes représentent des frontières approximatives dont le tracé peut ne pas avoir fait l'objet d'un accord définitif.

Source: World Health Organization/ National leprosy programmes – Organisation mondiale de la santé / Programmes nationaux de lutte contre la lèpre
Map: Global leprosy programme – Carte: Programme mondial de lutte contre la lèpre
© WHO 2017. All rights reserved – © OMS 2017. Tous droits réservés

507

Appendix A. This map shows the geographical distribution of new leprosy cases diagnosed in 2016. India and Brazil had the most cases in the world (Weekly epidemiological record: Global leprosy update, 2016, 2017). The map is meant to provide context on how Brazil's situation compares to other countries around the world.

Appendix B: Distribution of Leprosy Cases by State, 1920s-1940



Localidades	Total	Lavradores	Domésticos	Operários	Comerciários	Func. Públicos	Autores
MINAS GERAIS (fichamentos de 1926-1940)	7.557	3.559	2.345	115	38		DINIZ (2)
SÃO PAULO (fichamentos de 1924-1942)	21.320	6.087	5.968	1.336			Dados forn. pelo Serviço
PARANÁ (Hospital-Colônia São Roque, até 1938)	971	626 (64,4 %)	194 (19,9 %)	9	12 (1,2 %)		MOURA (3)
DISTRITO FEDERAL (fichamentos até 1936)	873	38	287	150	80	43	PORTUGAL (1)
DISTRITO FEDERAL (fichamentos até 1941)	1.507	33	244	73	49	20	MOTTA e MOURA COSTA (4)
MINAS GERAIS (Colônia Santa Izabel, 1935)	1.110	543 (50,1 %)	287 (26,5 %)	23 (2,1 %)	11 (1 %)	4 (0,3 %)	RODRIGUES DE ALBUQUERQUE (5)

PROFISSÃO

215

Appendix B. This chart shows the distribution of leprosy cases in some of Brazil's states from the 1920s to the 1940s. São Paulo had a much larger total number of cases in leprosaria (de Souza Campos, 1944). The increased volume of cases in São Paulo may be because of the stricter legislation in São Paulo. Notably, Santa Izabel in Minas Gerais is specifically mentioned. This is one of the two leprosaria I was able to visit. The chart indicates that the leprosaria was particularly large, housing 1,110 patients.

Appendix C: Brocos's *Saint Elizabeth Queen of Hungary curing the lepers as per Murillo*

Appendix C. I analyze Modesto Brocos's engraving from the early twentieth century in "Leprosy Stereotype for a Political Agenda: Brocos's Engraving ", Chapter I(Brocos, [19—?]).

Appendix D: Candido Portinari's *San Francisco de Assis*

Appendix D. Candido Portinari's painting shows similar biblical steretypes to Brocos's engraving (See Appendix C)(Portinari, 1944). The leprosy patients are in the lower plane of the artwork begging for aid. The depiction of leprosy patients at a lower level of the social hierarchy is reminiscent of Broco's work despite the different time periods.

Appendix E: Gonçalves's "Chorando"

"Chorando"

A minha "esperança" perdeu-se e foi dar
na casa onde vive a senhora saudade;
pois, mãos invisíveis, fecharam meu lar
e deram meus filhos à dona orfandade!

Havia um começo de felicidade,
nas asas do sonho que voava a cantar…
Mas, veio um bacilo, – que infelicidade! –
e toda a família se pôs a chorar!...

Depois, esta ausência, cruciante, infinita,
por causa da praga, chagosa e maldita,
que, como um sarcasmo, se prega marcando…

Por essa saudade, que não tem mais fim,
lá longe eles vivem chorando por mim,
enquanto eu por eles também vou chorando…

(Gonçalves, 2009)

Appendix F: Gonçalves's "Confidência"

"Confidência"

Rompe a alvorada. O dia se levanta.

Triste canário, uma canção solfeia,

em doce voz, em melodia santa,

implora a liberdade que planeja!

Também anseio o que o canário almeja

nesse cantar que a grande dor suplanta.

Ele, mais forte, canta o que deseja,

Como mais fraco, eu choro o que ele canta.

Um dia, eu disse ao pássaro, em segredo:

--Lamento o teu sofrer, o teu degredo,

já que nenhum de nós é crimonoso…

Lamento que te deem a mesma sorte,

que tua inôcencia a mesma dor suporte,

Quando tu nem ao menos és leproso!

(Gonçalves, 2009)

Appendix G: Gonçalves's "Meus Versos"

"Meus Versos"

Ide meus versos!... Como as folhas soltas
que desprendem, do seu seio amigo
e vão girando, por aí, revoltas,
buscando um novo pouso, um novo abrigo…

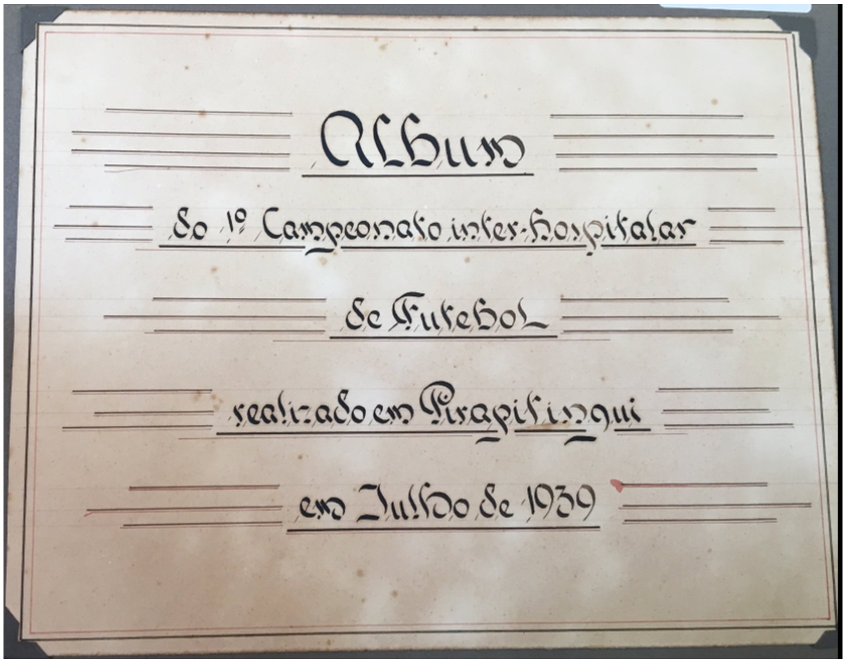
Ide. Mas não da glória o cume,
porque, marcados do meu sangue e pranto,
bem vos pode queimar o mesmo lume,
que fez as mágoas que a chorar eu canto!

Ide dizer o que eu dizer não pude;
pois me foi dado pela sorte rude;
um coração sadio num corpo enfermo!

Ide! Mas se vos for contrário o vento,
mofai na insipidez do esquecimento,
como eu mofei na solidão de um ermo!

(Gonçalves, 2009)

Appendix H: The Department of the Prophylaxis of Leprosy's Photo Album for 1939 Soccer Tournament



Album

do 1º Campeonato inter-Hospitalar

de Futebol

realizado em Pirapitingui

em Julho de 1939

Appendix G. This is a picture I took of the Department of Prophylaxis of Leprosy's photo album cover ("Album: Campeonato inter-hospitalar de Futebol realizado em Pirapitingui em Julho 1939," 1939). The album documents one of the patients' activities in the leprosaria, soccer. I included photographs that are evidence of activities in the leprosaria but maintain patient confidentiality in appendices H and I. Archive: Museu de Saúde Pública Emilio Ribas/Instituto Butantan

Appendix I: The Trophies from Pirpitingui's Soccer Tournament

Appendix H. This is a picture I took of the Department of Prophylaxis of Leprosy's photos ("Album: Campeonato inter-hospitalar de Futebol realizado em Pirapitingui em Julho 1939," 1939). The album documents one of the patients' activities in the leprosaria, soccer. This photograph shows the prizes of the soccer tournament, three trophies. Archive: Museu de Saúde Pública Emilio Ribas/Instituto Butantan

Appendix J: Parade at a Leprosarium

Appendix I. I took this photograph of the Department of Prophylaxis's photo album in the Emilio Ribas Museum of Public Health's arichives. The photograph shows a parade in Pirapitingui during a soccer tournament. Archive: Museu de Saúde Pública Emilio Ribas/Instituto Butantan

Appendix K: Gonçalves's "Miséria Extrema"

"Miséria Extrema"

A sombra de um casebre em que hei morado, gritando a teimosia da pobreza,
tinha um "tesouro" muito bem guardado,
que o não cambiava por qualquer riqueza!

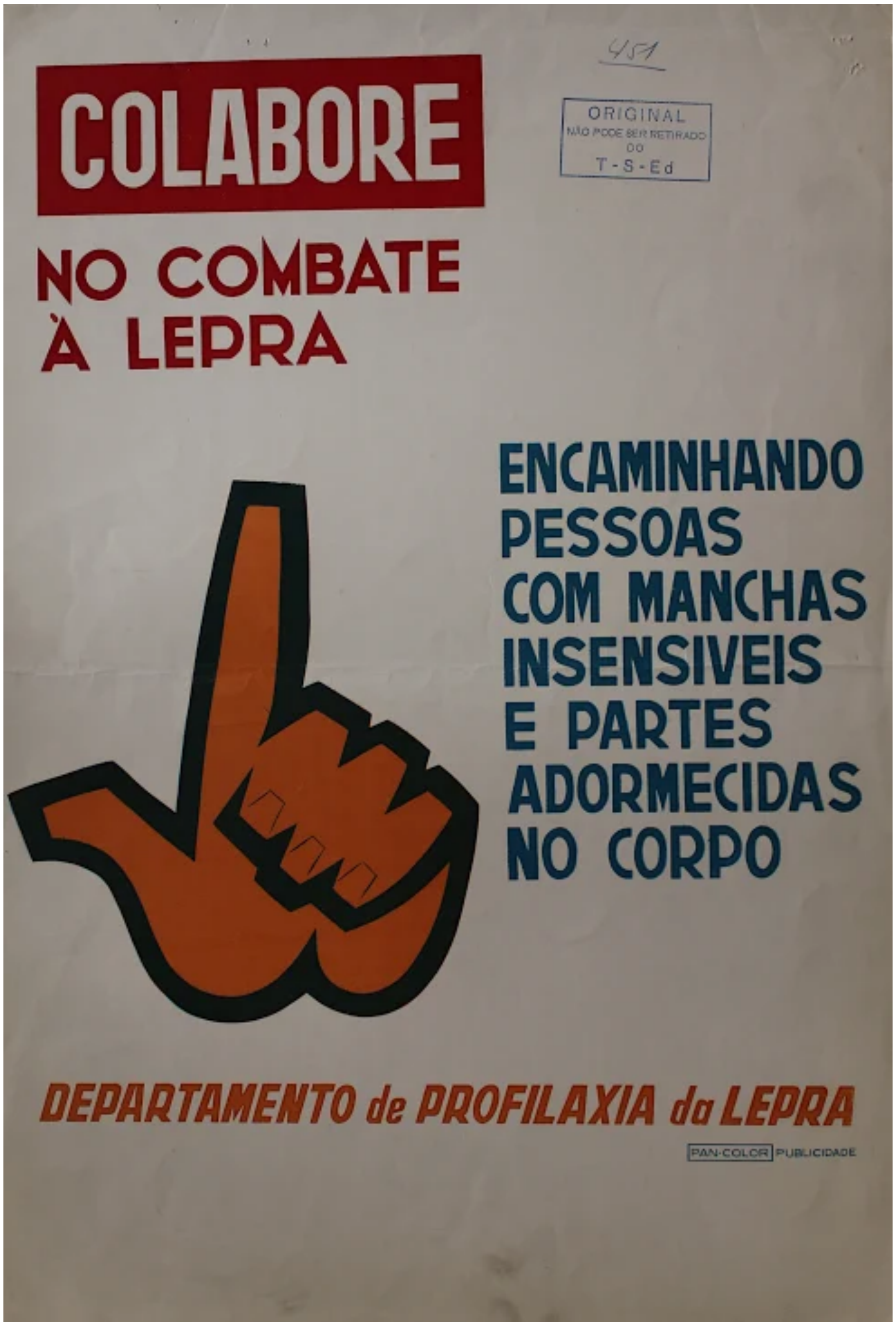
É que meu lar, primando em singeleza,
era por quatro jóias adornado.
Meus filhos!, quatro jóias de pureza
que o destino me deu como um legado!

Um dia… um virus, um brutal ladrão,
roubou-me as jóias; deu-me a solidão,
onde a saudade nasce, vinga e mora…

Sem o "tesouro" de valor tão nobre,
Lamento haver chorado por ser pobre,
Pois nunca fui tão pobre como agora…"

(Gonçalves, 2009)

Appendix L: The Department of Prophylaxis of Leprosy’s Poster Encouraging Collaboration



Appendix K. The Department of Prophylaxis of Leprosy released this poster between 1935 to 1969. I found this poster in the Emilio Ribas Museum of Public Health's and Butantan Institute's archive. I analyze the poster in "Government Control Of Human Bodies: Prophylaxis Poster and Julia’s Medical Record," Chapter II. Archive: Museu de Saúde Pública Emilio Ribas/Instituto Butantan

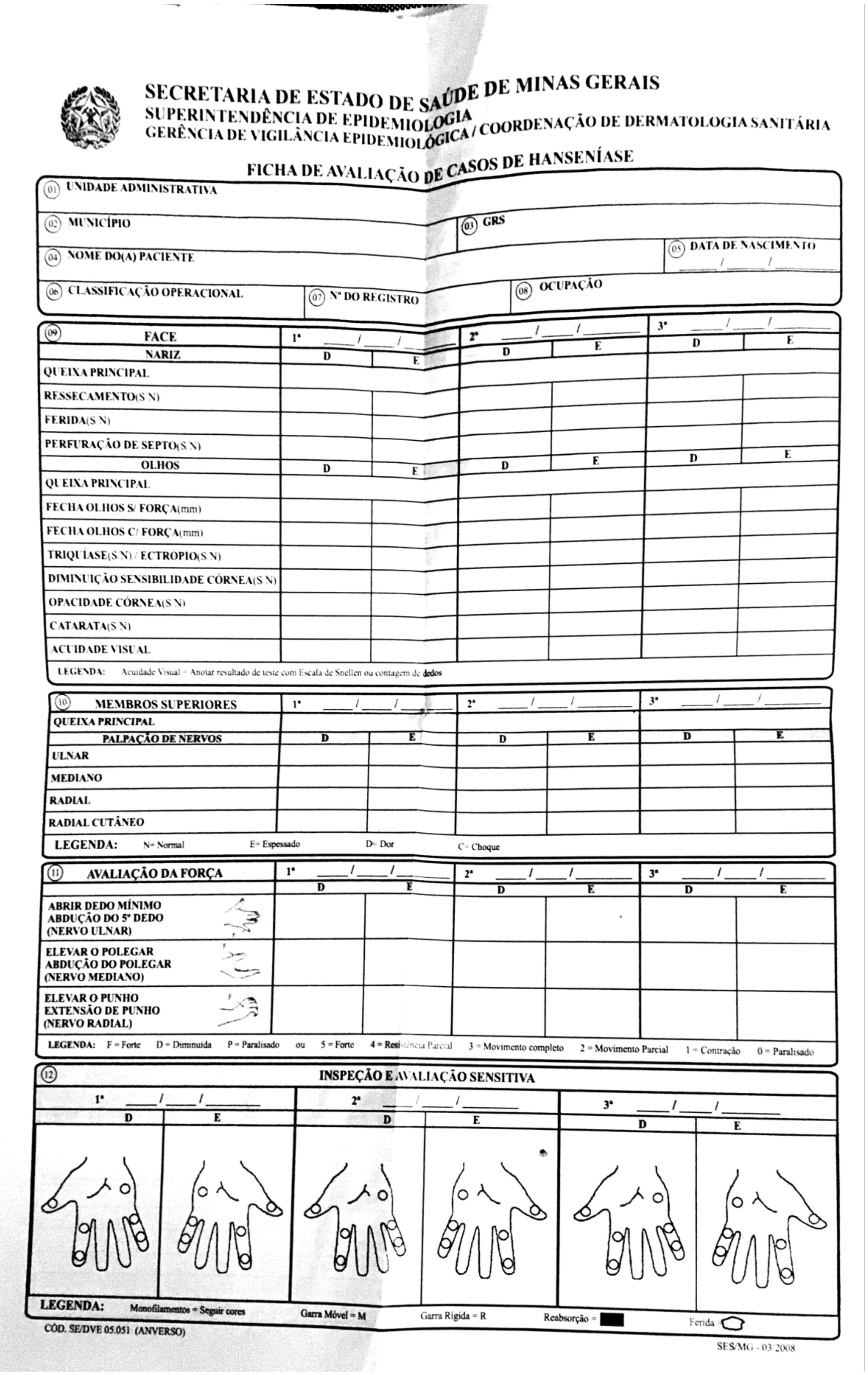
Appendix M The Department of Prophylaxis of Leprosy’s Poster on Heritability

Appendix L. This is one of the Department of Prophylaxis of Leprosy's posters from 1950. The poster advertises the children of leprosy as "perfectly healthy" in an attempt to minimize the discrimination of the children of leprosy patients and to encourage the adoption of those children. Archive: Museu de Saúde Pública Emilio Ribas/Instituto Butantan

Appendix N: Veganin's *Via Sacra*

Appendix M. Veganin (1950-1997), a patient and artist isolated in the Santa Isabel leprosarium, painted Via Sacra from 1987 to 1992 (Veganin, 1992)

Appendix O: State-Provided Patient Evaluation Form



SECRETARIA DE ESTADO DE SAÚDE DE MINAS GERAIS
SUPERINTENDÊNCIA DE EPIDEMIOLOGIA
GERÊNCIA DE VIGILÂNCIA EPIDEMIOLÓGICA / COORDENAÇÃO DE DERMATOLOGIA SANITÁRIA

FICHA DE AVALIAÇÃO DE CASOS DE HANSENÍASE

01 UNIDADE ADMINISTRATIVA

02 MUNICÍPIO

03 GRS

04 NOME DO(A) PACIENTE

05 DATA DE NASCIMENTO ____/____/____

06 CLASSIFICAÇÃO OPERACIONAL

07 Nº DO REGISTRO

08 OCUPAÇÃO

09 **FACE**	1ª ____/____/____		2ª ____/____/____		3ª ____/____/____	
NARIZ	D	E	D	E	D	E
QUEIXA PRINCIPAL						
RESSECAMENTO(S N)						
FERIDA(S N)						
PERFURAÇÃO DE SEPTO(S N)						
OLHOS	D	E	D	E	D	E
QUEIXA PRINCIPAL						
FECHA OLHOS S/ FORÇA(mm)						
FECHA OLHOS C/ FORÇA(mm)						
TRIQUIASE(S N) / ECTROPIO(S N)						
DIMINUIÇÃO SENSIBILIDADE CÓRNEA(S N)						
OPACIDADE CÓRNEA(S N)						
CATARATA(S N)						
ACUIDADE VISUAL						

LEGENDA: Acuidade Visual = Anotar resultado de teste com Escala de Snellen ou contagem de dedos

10 **MEMBROS SUPERIORES**	1ª ____/____/____		2ª ____/____/____		3ª ____/____/____	
QUEIXA PRINCIPAL						
PALPAÇÃO DE NERVOS	D	E	D	E	D	E
ULNAR						
MEDIANO						
RADIAL						
RADIAL CUTÂNEO						

LEGENDA: N= Normal E= Espessado D= Dor C= Choque

11 **AVALIAÇÃO DA FORÇA**	1ª ____/____/____		2ª ____/____/____		3ª ____/____/____	
	D	E	D	E	D	E
ABRIR DEDO MÍNIMO ABDUÇÃO DO 5º DEDO (NERVO ULNAR)						
ELEVAR O POLEGAR ABDUÇÃO DO POLEGAR (NERVO MEDIANO)						
ELEVAR O PUNHO EXTENSÃO DE PUNHO (NERVO RADIAL)						

LEGENDA: F = Forte D = Diminuida P = Paralisado ou 5 = Forte 4 = Resistência Parcial 3 = Movimento completo 2 = Movimento Parcial 1 = Contração 0 = Paralisado

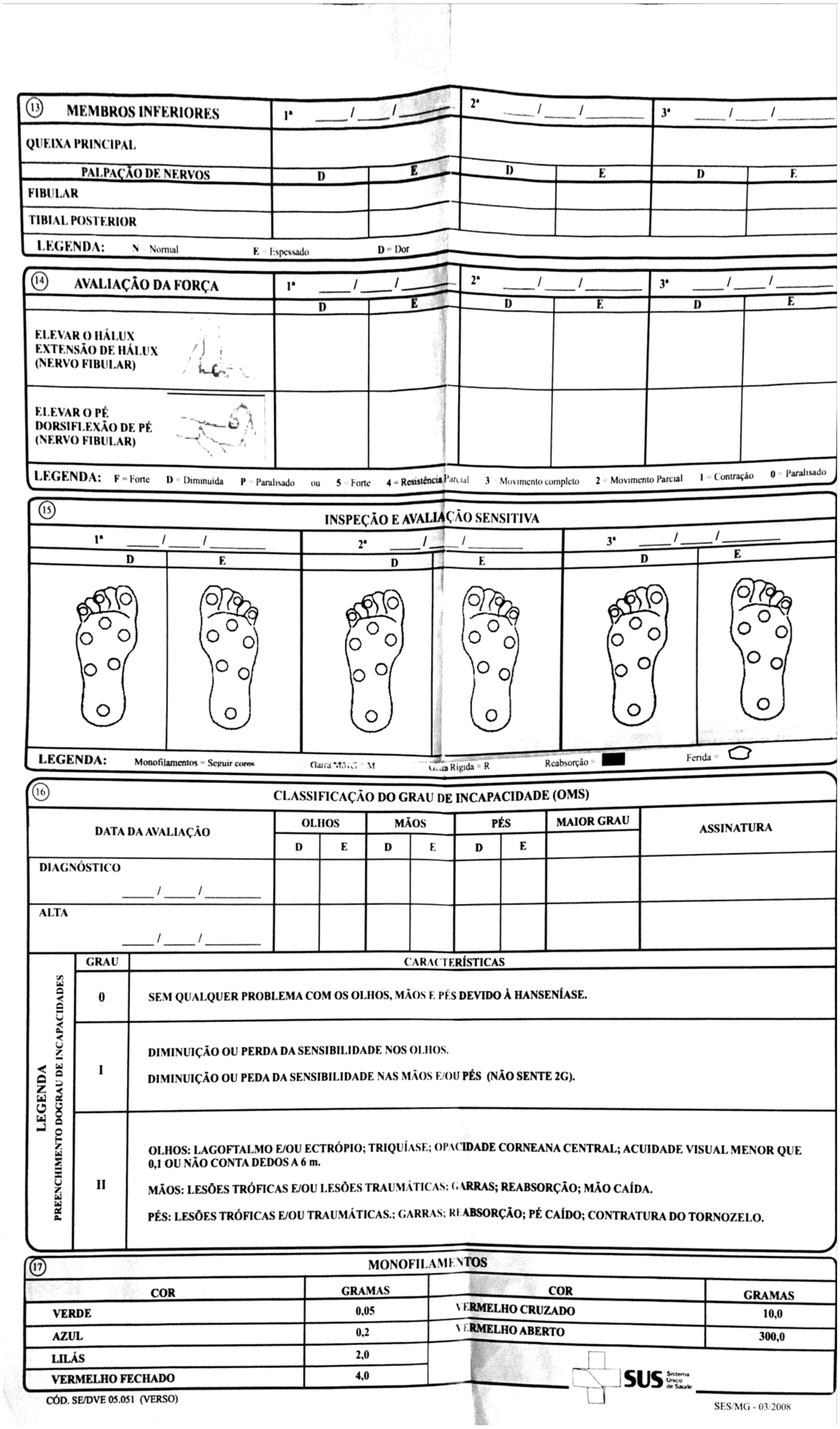
12 **INSPEÇÃO E AVALIAÇÃO SENSITIVA**

1ª ____/____/____		2ª ____/____/____		3ª ____/____/____	
D	E	D	E	D	E

LEGENDA: Monofilamentos = Seguir cores Garra Móvel = M Garra Rígida = R Reabsorção = ■ Ferida = ⬡

CÓD. SE/DVE 05.051 (ANVERSO)

SES/MG - 03/2008



⑬ MEMBROS INFERIORES	1ª ___/___/___		2ª ___/___/___		3ª ___/___/___	
QUEIXA PRINCIPAL						
PALPAÇÃO DE NERVOS	D	E	D	E	D	E
FIBULAR						
TIBIAL POSTERIOR						

LEGENDA: N = Normal E = Espessado D = Dor

⑭ AVALIAÇÃO DA FORÇA	1ª ___/___/___		2ª ___/___/___		3ª ___/___/___	
	D	E	D	E	D	E
ELEVAR O HÁLUX EXTENSÃO DE HÁLUX (NERVO FIBULAR)						
ELEVAR O PÉ DORSIFLEXÃO DE PÉ (NERVO FIBULAR)						

LEGENDA: F = Forte D = Diminuída P = Paralisado ou 5 = Forte 4 = Resistência Parcial 3 = Movimento completo 2 = Movimento Parcial 1 = Contração 0 = Paralisado

⑮

INSPEÇÃO E AVALIAÇÃO SENSITIVA

1ª ___/___/___		2ª ___/___/___		3ª ___/___/___	
D	E	D	E	D	E

LEGENDA: Monofilamentos = Seguir cores Garra Móvel = M Garra Rígida = R Reabsorção = ■ Ferida = ⬡

⑯

CLASSIFICAÇÃO DO GRAU DE INCAPACIDADE (OMS)

DATA DA AVALIAÇÃO	OLHOS		MÃOS		PÉS		MAIOR GRAU	ASSINATURA
	D	E	D	E	D	E		
DIAGNÓSTICO ___/___/___								
ALTA ___/___/___								

LEGENDA
PREENCHIMENTO DOGRAU DE INCAPACIDADES

GRAU	CARACTERÍSTICAS
0	SEM QUALQUER PROBLEMA COM OS OLHOS, MÃOS E PÉS DEVIDO À HANSENÍASE.
I	DIMINUIÇÃO OU PERDA DA SENSIBILIDADE NOS OLHOS. DIMINUIÇÃO OU PEDA DA SENSIBILIDADE NAS MÃOS E/OU PÉS (NÃO SENTE 2G).
II	OLHOS: LAGOFTALMO E/OU ECTRÓPIO; TRIQUÍASE; OPACIDADE CORNEANA CENTRAL; ACUIDADE VISUAL MENOR QUE 0,1 OU NÃO CONTA DEDOS A 6 m. MÃOS: LESÕES TRÓFICAS E/OU LESÕES TRAUMÁTICAS; GARRAS; REABSORÇÃO; MÃO CAÍDA. PÉS: LESÕES TRÓFICAS E/OU TRAUMÁTICAS.; GARRAS; REABSORÇÃO; PÉ CAÍDO; CONTRATURA DO TORNOZELO.

⑰

MONOFILAMENTOS

COR	GRAMAS	COR	GRAMAS
VERDE	0,05	VERMELHO CRUZADO	10,0
AZUL	0,2	VERMELHO ABERTO	300,0
LILÁS	2,0		
VERMELHO FECHADO	4,0		

SUS Sistema Único de Saúde

CÓD. SE/DVE 05.051 (VERSO)

SES/MG - 03/2008

Bibliography

. (1945). Prontuarios de leprosarios do São Paulo. Medical record. Museu de Saúde Pública/ Instituto Butantan.

AIDSinfo. (2018). *UNAIDS*. Retrieved from http://aidsinfo.unaids.org/#

Album: Campeonato inter-hospitalar de Futebol realizado em Pirapitingui em Julho 1939. (1939). São Paulo, Brazil: Departamento de Prophylaxia da Lepra.

Boletim Epidemiológico: Hanseníase. (2018). Retrieved from http://portalarquivos2.saude.gov.br/images/pdf/2018/janeiro/31/2018-004-Hanseniase-publicacao.pdf

Boti, N. A., K. (2008). A Via Sacra da Hanseníase de Veganin. *Revista Brasileira de Enfermagem, 61*, 676-681.

Brandsma, J. W., & Van Brakel, W. H. (2003). WHO disability grading: operational definitions. *Lepr Rev, 74*(4), 366-373.

Brocos, M. ([19—?]). Santa Izabel Rainha da Ungria curando os leprosos segundo Murillo. In.

Caldeira, J., de Carvalho, F., Marcondes, C., & Goes de Paula, S. (1997). *Viagem pela História do Brasil* (2 ed.): Companhia das Letras.

Cule, J. (1999). *The stigma of leprosy: its historical origins and consequences with particular reference to the laws of Wales*. Paper presented at the International Congress on the Evolution and Palaeoepidemiology of the Infectious Diseases 3 (ICEPID), University of Bradford.

de Castro Santos, L. A. F., L.; Fernandes de Menezes, R. (2008). Contrapontos da história da hanseníase no Brasil: cenários de estigma e confinamento. *Revista Brasileira de Estudos de População, 25*(1), 167-190.

de Souza Campos, N. B., L. M.; Rolberg, A. (1944). Tratado de Leprologia: Epidemiologia e Profilaxia. In *Tratado de Leprologia: Epidemiologia e Profilaxia* (Vol. 5, pp. 215). Rio de Janeiro, Brazil: Serviço Nacional da Lepra.

Decreto N. 16.300, (1923).

Deputados aprovam pensão a portadores de hanseníase isolados até 1986. (2011). *Morhan Nacional*. Retrieved from http://www.morhan.org.br/noticias/288/deputados_aprovam_pensao_a_portadores_de_hanseniase_isolados_ate_1986

Elimination of discrimination against persons affected by leprosy and their family members, A/HRC/29/L.10 C.F.R. (2015).

Espiritismo. *Brasiliana Collection*. Retrieved from https://library.brown.edu/create/brasiliana/espiritismo/

Essential Medicines and Health Products Information Portal: Treatment of Leprosy. (2017). Retrieved from http://apps.who.int/medicinedocs/en/d/Jh2988e/5.html

Fontoura, A. d. A. d., Barcelos, A. H. F., & Borges, V. T. (2003). Revealing a history of exclusion: the experience at Hospital-Colônia Itapuã Data and Research Center %J História, Ciências, Saúde-Manguinhos. *10*, 397-414.

Francis, P. (2013a). ADDRESS OF POPE FRANCIS [Press release]. Retrieved from http://m2.vatican.va/content/francesco/en/speeches/2013/october/documents/papa-francesco_20131004_poveri-assisi.html

Francis, P. (2013b). ADDRESS OF POPE FRANCIS TO THE COMMUNITY OF THE PONTIFICAL ECCLESIASTICAL ACADEMY [Press release]. Retrieved from http://m2.vatican.va/content/francesco/en/speeches/2013/june/documents/papa-francesco_20130606_pontificia-accademia-ecclesiastica.html

Francis, P. (2015). HOMILY OF HIS HOLINESS POPE FRANCIS [Press release]. Retrieved from https://w2.vatican.va/content/francesco/en/homilies/2015/documents/papa-francesco_20150215_omelia-nuovi-cardinali.html

Francis, P. (2018). PRAYER OF HIS HOLINESS POPE FRANCIS [Press release]. Retrieved from http://w2.vatican.va/content/francesco/en/prayers/documents/papa-francesco_preghiere_20180330_via-crucis.html

Frequently Asked Questions on Leprosy. (2013). Retrieved from http://apps.searo.who.int/PDS_DOCS/B5044.pdf

Ghosh, S., & Chaudhuri, S. (2015). Chronicles of Gerhard-Henrik Armauer Hansen's Life and Work. *Indian J Dermatol, 60*(3), 219-221. doi:10.4103/0019-5154.156310

Global Leprosy Strategy 2016−2020: Accelerating towards a leprosy-free world. (2016). Retrieved from World Health Organization:

Goffman, E. (1986). *Stigma : notes on the management of spoiled identity*. .

Gonçalves, J. X., F. C. (2009). *Flores de Outono*.

Hansen’s Disease (Leprosy): Transmission. (2017). Retrieved from https://www.cdc.gov/leprosy/transmission/index.html

Health statistics and information: WHOQOL: Measuring Quality of Life. (2018). Retrieved from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

Henry, M., GalAn, N., Teasdale, K., Prado, R., Amar, H., Rays, M. S., . . . Das, P. K. (2016). Factors Contributing to the Delay in Diagnosis and Continued Transmission of Leprosy in Brazil--An Explorative, Quantitative, Questionnaire Based Study. *PLoS Negl Trop Dis, 10*(3), e0004542. doi:10.1371/journal.pntd.0004542

Herath, S., Navinan, M. R., Liyanage, I., Rathnayaka, N., Yudhishdran, J., Fernando, J., Sirimanne, G., Kulatunga, A. (2015). Lucio's phenomenon, an uncommon occurrence among leprosy patients in Sri Lanka. *BMC research notes, 8*(672). doi:10.1186/s13104-015-1671-1

IDF Diabetes Atlas. (2017). (8 ed.).

Law, A. S. (1999). *The last leprosy communities…and the people who call them home*. Paper presented at the International Congress on the Evolution and Palaeoepidemiology of the Infectious Diseases 3 (ICEPID), University of Bradford.

Lesson 1: Introduction to Epidemiology, Section 9: Natural History and Spectrum of Disease. (2012). *Principles of Epidemiology in Public Health Practice, Third Edition*

An Introduction to Applied Epidemiology and Biostatistics. Retrieved from https://www.cdc.gov/ophss/csels/dsepd/ss1978/lesson1/section9.html

Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *27*(1), 363-385. doi:10.1146/annurev.soc.27.1.363

Ma, H. I., Saint-Hilaire, M., Thomas, C. A., & Tickle-Degnen, L. (2016). Stigma as a key determinant of health-related quality of life in Parkinson's disease. *Qual Life Res, 25*(12), 3037-3045. doi:10.1007/s11136-016-1329-z

Marx, C., Benecke, C., & Gumz, A. (2017). Talking Cure Models: A Framework of Analysis. *Front Psychol, 8*, 1589. doi:10.3389/fpsyg.2017.01589

Monteiro, Y. N. (1987). Hanseníase: História e Poder no Estado de São Paulo. *Hansenologia Inernationalis: Hanseníase e outras doenças infecciosas, 12*(1), 1-7.

Morhan. (2011a). Indenizações: Lei 11.520/2007.

Morhan. (2011b). Movimento de Reintegração das Pessoas Atingidas pela Hanseníase. Retrieved from http://www.morhan.org.br/

Neglected tropical diseases. (2018). Retrieved from https://www.who.int/neglected_diseases/diseases/en/

Opromalla, P. A. L., R. (2011). Controle da hanseníase no Estado de São Paulo: análise histórica. *Rev. Saude Publica, 45*(1), 195-203.

Phelan, J., Link, B. G., & Dovidio, J. F. (2008). "Stigma and Prejudice: One Animal or Two?". *Soc Sci Med, 67*(3), 358-367. doi:10.1016/j.socscimed.2008.03.022

Picon, R. F., F.; Moreira, L.; Riegel, G.; Fuchs, S. (2012). Trends in Prevalence of Hypertension in Brazil: A Systematic Review with Meta-Analysis. *PLOS ONE, 7*(10).

Portinari, C. (1944). São Francisco de Assis. In. São Paulo, São Paulo, Brazil.

Ribas, E. (1916). *Lepra, sua frequencia no Estado de São Paulo, meios profiláticos aconselháveis*. Paper presented at the º Congresso Médico Paulista, São Paulo, Brazil.

Rousseau, C. M.-B., A.; Moreau, S. (2001). Trauma and Extended Separation from Family among Latin American and African Refugees in Montreal. *Psychiatry: Interpersonal and Biological Processes, 64*(1), 40-59.

Saint Elizabeth of Hungary. (2018). Retrieved from https://www.britannica.com/biography/Saint-Elizabeth-of-Hungary

Sato, H., & Frantz, J. E. (2005). Termination of the leprosy isolation policy in the US and Japan : Science, policy changes, and the garbage can model. *BMC Int Health Hum Rights, 5*(1), 3. doi:10.1186/1472-698x-5-3

Saúde, M. d. Campanha Hanseníase. Retrieved from http://portalarquivos.saude.gov.br/campanhas/hanseniase/

Saúde, M. d. (2019). Agentes Comunitários de Saúde e Agentes de Controle de Endemias. *Trabalho, Educação e Qualificação*. Retrieved from http://portalms.saude.gov.br/trabalho-educacao-e-qualificacao/gestao-e-regulacao-do-trabalho-em-saude/agentes-comunitarios

Tekiner, H. (2015). Aretaeus of Cappadocia and his treatises on diseases. *Turk Neurosurg, 25*(3), 508-512. doi:10.5137/1019-5149.Jtn.12347-14.0

Veganin, L. (1992). Via Sacra. In.

Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophr Bull, 33*(6), 1312-1318. doi:10.1093/schbul/sbl076

Weekly epidemiological record: Global leprosy update, 2016. (2017). Retrieved from http://apps.who.int/iris/bitstream/handle/10665/258841/WER9235.pdf?sequence=1

Weekly Epidemiological Record: Global leprosy update, 2017. (2018). Retrieved from http://apps.who.int/iris/bitstream/handle/10665/274289/WER9335.pdf?ua=1