Brazil, India, and Japan:
Identifying Critical Gaps in Three National Leprosy Control Programs and Policy Recommendations to Address Them

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Abstract

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Background: Leprosy is one of the oldest contemporary diseases in the world with assumed descriptive cases of the disease dating back to the 5th century BC. In 2000, the WHO announced the global elimination of leprosy as a public health problem as the WHO defines elimination as a prevalence of less than one case per every 10,000 people. However, leprosy transmission has continued to date. Recent efforts to investigate the link between SES and leprosy have found socioeconomic indicators to be significant predictors of disease. Leprosy, also known as Hansen's disease, is caused due to a bacterial infection known as *Mycobacterium leprae.* Diagnosis of leprosy is mainly based on three cardinal signs: the presence of hypopigmented or erythematous skin lesions, the thickened or enlarged peripheral nerves with loss of sensation and/or weakness of the muscles, and/or the presence of acid-fast bacilli in a slit-skin smear. **Methods:** Herein, the national leprosy programs of Brazil, India, and Japan were assessed and compared through the Five "E" Approach. The Five-E model was first developed to evaluate the appropriateness and effectiveness of social welfare policy . The proposed model identified five key questions that result in an overview of a policy or program's implementation. **Results:** Through the five-E approach, it has been ascertained that although all three countries have made major strides toward leprosy control, there remain key gaps that prohibit the success of these programs. It was determined that one of the key factors that is not adequately addressed by any national leprosy control program is that of socioeconomic status and the role it plays in the transmission and treatment of leprosy. **Discussion & Recommendations:** Given the identification of this key gap, three main recommendations have been made herein to address the role of socioeconomic status in leprosy control. These recommendations include social protection initiatives, the strengthening of activities related to socioeconomic status, and the engagement of care providers. By integrating these recommendations into the national leprosy control programs, Brazil, India, and Japan can hope to more adequately and comprehensively approach the control of leprosy.

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Chapter One: Introduction & Background

Few diseases have affected the world so much so that they have become a part of commonplace linguistics- leprosy is among them. The common English idiom referencing being a “social leper” is a testament to the vast implications that leprosy can have on the lives and well-being of patients. Leprosy is an infectious disease caused by the *Mycobacterium leprae* bacteria and primarily affects the skin and peripheral nervous system of infected individuals (WHO 2018). While the incubation period for leprosy has been observed to vary anywhere from six months to twenty years (Fischer 2017), leprosy is treatable through the administration of multi-drug therapy and long-term disability can be prevented, if detected early (WHO 2018).

Leprosy is one of the oldest contemporary diseases in the world with assumed descriptive cases of the disease dating back to the 5th century BC (Kerr-Pontes, Barreto et al. 2006). In 2000, the WHO announced the global elimination of leprosy as a public health problem as the WHO defines elimination as a prevalence of less than one case per every 10,000 people (WHO 2018). However, leprosy transmission has continued to date. In 2016 alone, over 200,000 new cases of leprosy were reported (WHO 2018). Astonishingly, 95% of all new leprosy cases originate from twenty-two countries which have been deemed the “global priority countries” in leprosy elimination (Kerr-Pontes, Barreto et al. 2006).

The fact that all twenty-two of the “global priority countries” are low- and middle-income countries, suggests that leprosy does not impact all populations in the same way. Over the centuries, much research has been done to elucidate the genetic, environmental, and behavioral risk factors for contracting leprosy (Hatta 2003, White and Franco-Paredes 2015). However, there remains a gap in thoroughly understanding the mechanisms through which socioeconomic characteristics determine risk of leprosy.

Understanding the ways in which socioeconomic status (SES) impacts leprosy risk is especially important given that a strong link has been demonstrated between socioeconomic status and risk of infectious diseases, and more specifically neglected tropical diseases (Kerr-Pontes, Barreto et al. 2006). Given the scarcity of historical research directly linking socioeconomic status to leprosy, countries still struggling to control the transmission of the disease have failed to integrate interventions addressing the socioeconomic risk factors into their national action plans (Houweling, Karim-Kos et al. 2016). Recent efforts to investigate the link between SES and leprosy have found socioeconomic indicators to be significant predictors of disease (Moet, Meima et al. 2004, Pescarini, Strina et al. 2018).

It is critical therefore, that given recent findings linking SES to leprosy, countries with endemic leprosy adapt their national policies to include consideration of these risk factors. Herein, the national leprosy policies of three countries -- India, Brazil, and Japan -- are examined and recommendations for the ways in which they can be adapted to produce a more comprehensive, and ultimately more effective, leprosy control program are given.

Chapter Two: Review of Literature

Descriptive Epidemiology

Definition of leprosy

Leprosy, also known as Hansen's disease, is caused due to a bacterial infection known as *Mycobacterium leprae* (WHO 2018). It is a chronic condition that affects the skin, nervous system, and mucous membranes. The disease is also associated with significant stigma due to its long-term consequences of deformities and disabilities (White and Franco-Paredes 2015).

Immunopathology

Clinical manifestations

M. leprae is an obligate intracellular organism that is rod-shaped (bacillus). It is known as an acid-fast bacterium because of the high mycolic acid content in its cell walls (Talhari, Talhari et al. 2015). According to studies, this bacterium grows best in temperatures ranging from 27-33 degrees Celsius, correlating with its affinity to affect the skin, mucous membranes, and nerve segments close to the skin, all of which are cooler areas of the body. M.leprae is also known to have a long incubation period, on average of 5 years, which is why symptoms can appear anywhere within a year or take as long as 20 years or more (Hatta 2003, Talhari, Talhari et al.

2015). While leprosy transmission is not fully understood, it has been theorized in the literature that the disease is likely spread via respiratory droplets (Talhari, Talhari et al. 2015)

Early manifestations of leprosy mainly involve skin lesions with associated neuropathy. Physical examination of patients shows hypopigmented or erythematous lesions with diminished or loss of sensation within the patches (Talhari, Talhari et al. 2015). Other reported findings, usually appearing later, include weakness of the hands, foot drop, facial paralysis, collapsed nose, or perforated nasal septum. These later findings correlate with the extent of nerve involvement. Long-term consequences, seen especially in untreated individuals, include disabilities involving the eyes (lagophthalmos and corneal ulcerations) causing blindness, crippling paralysis of the hands and feet, loss of eyebrows, and nose disfigurement (Hatta 2003, Talhari, Talhari et al. 2015).

The number of skin lesions and severity of symptoms, such as neuropathy, varies based on the immune response of the affected patient (Hatta 2003). The higher the patient's immune response, the less severe the disease burden. A patient's immune response can be affected by a variety of factors including genetic predisposition, nutritional status, and environmental factors (Hatta 2003).

The WHO classification system for leprosy has two categories, Paucibacillary (PB) and Multibacillary (MB)(Goulart and Goulart 2008, WHO 2019). PB is defined as five or less lesions without detectable bacteria on skin smears, while MB is defined as six or more lesions that are smear positive(Goulart and Goulart 2008) . The type and duration of treatment is dependent on the classification of leprosy type and the age of the patient. Since this system was designed to use in circumstances where there is a lack of sufficient clinical expertise or lab support, it is known to be problematic because it leads to misclassification, resulting in undertreatment of some cases.

A more detailed classification system, known as the Ridley-Jopling classification, categorizes leprosy patients not only on the basis of the number of skin lesions, but also on the severity of neuropathy (Talhari, Talhari et al. 2015). The Ridley-Jopling classification system includes six categories, listed in order of increasing severity: tuberculoid (TT), borderline tuberculoid (BT), mid-borderline (BB), borderline lepromatous (BL), Lepromatous (LL), and intermediate (I) leprosy.

Diagnosis of leprosy is mainly based on three cardinal signs: the presence of hypopigmented or erythematous skin lesions, the thickened or enlarged peripheral nerves with loss of sensation and/or weakness of the muscles, and/or the presence of acid-fast bacilli in a slit-skin smear (Talhari, Talhari et al. 2015). As early leprosy and PB leprosy may not manifest with skin lesions and positive smears as quickly, using the above clinical signs as diagnostic markers makes early diagnosis difficult. Consequently, there have been other laboratory tests developed which incorporate microbiological techniques, such as Polymerase Chain Reaction (PCR) and Enzyme-Linked Immunosorbent Assay (ELISA), to validate symptomatic diagnosis. The challenges associated with these two tests however are that ELISA has been observed to have low accuracy in the case of PB leprosy and PCR, while associated with higher accuracy, is not commercially available and difficult to perform in most primary care settings (Goulart and Goulart 2008, Talhari, Talhari et al. 2015).

Significance of Problem

Global context of Leprosy

While there have been cases of leprosy reported worldwide, the highest number of cases reported are from India and Brazil, with Indonesia being third(White and Franco-Paredes 2015).

According to the WHO distribution report in 2016, India reported 127, 326 new cases, accounting for 60% of the global case load(White and Franco-Paredes 2015). Brazil reported 26, 395 cases which accounted to 13% of the distribution, but actually has a higher annual new case detection rate than India(Goulart and Goulart 2008, WHO 2019). Indonesia reported 17, 202 new cases, accounting to 8%. While no other country reported more than 10000 cases, there were quite a few African countries that reported high numbers such as the Democratic Republic of Congo, Ethiopia, Madagascar and more(WHO 2019).

Overview of Leprosy in India

Evidence from ancient burial sites suggests that leprosy in India goes back to Vedic times, in fact, the ancient Sanskrit texts is the oldest written reference to leprosy (Robbins, Tripathy et al. 2009). It refers to the disease as “that which has originated in the body and upon the skin, the white mark begotten of corruption” (Robbins, Tripathy et al. 2009). As in many places around the world, leprosy was looked at through a religious lens and considered the mark of moral failure and sin. During Vedic times, the Hindu ritual of cremation after death was not awarded to people affected by leprosy, rather they were often buried alive so as not to upset the Gods. This stigmatizing is still present in parts of India where persons affected by leprosy are often denied funeral rites by their communities (Muir and Lowe 1933, Robbins, Tripathy et al. 2009). Historically persons affected by leprosy in India are ostracized and forced to live in isolation from the rest of society(Muir and Lowe 1933). However, it wasn’t until British colonial rule that an act was passed to set legal precedence for the institutionalizing of leprosy patients(1898). Under the Leprosy Act of 1898, persons affected by leprosy were arrested, and institutionalized in “leper asylums”. Furthermore, gender segregation was maintained in asylums was seen as a leprosy control measure against reproduction (1898). The 1989 Leprosy Act also prohibited leprosy patients from engaging in trade and penalized anyone found employing them . Although the act was repealed in 2011, it left a legacy of stigmatization and the false perception of persons affected by leprosy as beggars(1898, Muir and Lowe 1933).

Today India has over 16 national and states laws, most of which relics of the British Raj, that discriminate, are directly or indirectly, against individuals affected by leprosy (Singh, Sinha et al. 2009). For example, until this year the Indian Divorce Act of 1869 permitted divorce/separation/ dissolution of a marriage on the grounds of leprosy (Mandhani 2019). Through the act, the spouse of the leprosy affected person could legally deny alimony. The act was repealed recently due to the efforts of activist and leprosy organizations operating in India.

Although India declared that it had “eliminated” leprosy in 2005, it has the highest rate of cases in the world (Noordeen 2015). According to the WHO more than 60 percent of total global cases are found in India (WHO 2019). The government’s declaration of elimination was premature, as the country didn’t implement post eradication elimination policies (Noordeen 2015). It was concluded by the Indian Council of Medical Research the reason for re-emergence is the low voluntary reporting due to lack of awareness along with stigma and discrimination. The Indian Journal of Medical Research quotes, “numbers of leprosy cases are increasing…probably due to discontinuation of surveillance activities, distribution of multidrug therapy, deformity prevention and management performed by leprosy workers…” (Jain 2012). A retrospective study was conducted at the Medical College Hospital in Northern India which recorded outpatient leprosy cases from the year 2009 and 2014 (Dimri, Gupta et al. 2016). The data showed that 129 individuals out of 47,465 were diagnosed with leprosy and the age group ranged from 18 to 60 years, demonstrating hyperendemicity in this area. The study concluded that India is still a major concern because of its high prevalence rate in rural areas of the country (Dimri, Gupta et al. 2016).

Overview of Leprosy in Brazil

It is likely that leprosy was first introduced to Brazil by the Portuguese, and then later through European immigrants and the slave trade (Mark 2017). Although leprosy was reported on in the 1600s and efforts were made towards the seclusion of persons with leprosy, forced isolation of leprosy affect persons become the preferred method of dealing with the disease after the 19th century(Rosa Maciel, Oliveira et al. 2003) . During the 20th century, lack of understanding and negative perceptions about leprosy spurred the creation the Sao Paulo model. This model was comprised of three components that gave guidance for the handling of leprosy, “leprosario”, “dispensario”, and “preventorio” (Rosa Maciel, Oliveira et al. 2003).

Today, Brazil has the second highest number of new leprosy cases in the world (Schweickardt and Xerez 2015). Within Brazil, a majority of leprosy’s burden of disease falls within metropolitan areas in the North and Midwest regions of the country (Pescarini, Strina et al. 2018). Furthermore, results from a national survey, conducted between 2001 and 2011, show that there was a significant reduction in national incidence of leprosy during the ten-year study period (Freitas, Duarte et al. 2016). In 2001, 45,874 new cases of leprosy were reported in Brazil whereas in 2011, only 33,955 new cases of leprosy were reported, demonstrating a reduction of almost 26% (Nobre, Illarramendi et al. 2017). The country’s leprosy control efforts rely predominantly on multi-drug therapy (MDT) treatments for infected individuals. However, despite the improvement in care and the related reduction in incidence, leprosy remains a major public health concern in Brazil.

Overview of Leprosy in Japan

In 1907, Japan passed Cabinet Bill, Law No. 11, the Act on Leprosy Prevention, which was later amended and became the Leprosy Prevention Law (Sato and Narita 2003). In the original law, it was stated that patients who were identified as having leprosy should be cared for in their respective homes. Shortly after, officials in the Ministry of Internal Affairs (MIA) voiced concerns claiming that leprosy patients posed a threat to community security (Sato and Narita 2003). As such, they asserted that stricter measures needed to be taken to ensure the safety of communities by isolating leprosy patients. The revision of Law No. 11 addressed these concerns and dictated that leprosy patients be admitted to “leprosaria,” or isolation facilities, upon diagnosis (Sato 2002). By 1909, five public leprosaria were established throughout different regions of the country. The directors chosen to run the day-to-day operations of these facilities were all ex-directors of police precincts or prisons (Sato and Narita 2003). Given the fear that came to be associated with the leprosaria, those affected by leprosy began to try to hide their symptoms from physicians and officials to avoid being involuntarily placed in isolation. As support for isolation policies strengthened, the governing body revised the Leprosy Prevention Law, originally passed in 1907, to codify a new policy on absolute segregation(Sato 2002). The revision established the legal basis for the enforced isolation of patients, the prohibition of patients’ leave without permission from appropriate authorities, and the punishment of inpatients who disturbed the peace at leprosaria. Furthermore, the law did not incorporate any clear standard procedure for discharge of patients or make provisions for outpatient treatment.

The recognition of the inhumane nature of such a policy, which continued to isolate patients well after their recovery, drove a successful movement for leprosy policy reform and the law was repealed in 1996 (Sato 2002).

Social Determinants of Health

The distribution of adverse health outcomes is not uniform in our world; health is determined by a wide range of social, cultural, and political realities. However, across nations and cultures, it has been found that certain characteristics put populations at disproportionately higher risks of adverse health outcomes than their counterparts (Braveman and Gottlieb 2014). As such, in recent times, there has been a push to highlight the role of social factors in determining health outcomes.

The public health community's growing focus on the social determinants of health (SDH) has led to research interest in factors shaping the health and access to healthcare services of communities and individuals(Braveman and Gottlieb 2014). There is increasing evidence linking existing knowledge of the biological pathways of disease with social factors; for example, it has been found that in slums around the world which face problems such as crowded living conditions and inadequate WASH infrastructure, the spread of infectious disease occurs much faster than in other regions. Longitudinal and cross-sectional studies conducted in the past few decades reveal a strong association between social disparities, especially socioeconomic, and a range of health outcomes (Braveman and Gottlieb 2014).

Data collected from around the world shows a strong association between various health indicators and the social position or socioeconomic resources of an individual (Braveman and Gottlieb 2014). According to research in the U.S. and Europe, there is a stepwise gradient pattern seen in the relationship between socioeconomic background and health indicators (Braveman and Gottlieb 2014). This means that an individual's health sees improvement in association to an increase in the person's resources or rise in social position.

While increasing evidence suggests that social factors play a critical role in shaping health, the mechanism is not understood (Braveman and Gottlieb 2014). There are confounding factors that need to be considered and more research is needed to confirm a causal relationship. The use of the traditional criteria for examining the results is in question, and therefore about the strength of the evidence supporting SDH in influencing health.

Socio-economic Factors & Leprosy

Throughout history, leprosy has been heavily stigmatized, and people affected by leprosy have been forced to live as outcasts exiled from their communities. In fact, when people think of leprosy, the image that is conjured up is of person with severe deformities, and often a beggar. It is not surprising then that there is a strong association of poverty and leprosy.

For a long time, researchers have striven to better understand the association of socioeconomic status (SES) and leprosy. Several studies have identified key social factors as risk markers for increased leprosy transmission (Pescarini, Strina et al. 2018). A case-control study based in North-east Brazil found a connection between social factors associated with SES and leprosy prevalence (Kerr-Pontes, Barreto et al. 2006). The study carried out over nine years concluded that a range of SES factors, including food shortages, poor WASH conditions and low education, were risk factors for leprosy. Other studies have collaborated these findings with their own results; a study in Bangladesh highlighted food shortage as a risk factor for leprosy, studies in

Malawi and Indonesia identified living conditions, especially crowded living space and household contact status, as risk factors for leprosy (Feenstra, Nahar et al. 2013, Pescarini, Strina et al. 2018).

Existing Global Leprosy Control Strategies

In 2016, the World Health Organization launched a strategy titled the "Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world," produced through consultations with a diverse set of stakeholders in the years prior (WHO 2018). The primary objective of the strategy was to revive leprosy control efforts globally, with a special emphasis on the prevention of leprosy-related disabilities. It sought to do so through a series of interventions which improved healthcare access and coverage among the most marginalized subpopulations globally and targeted campaigns for early detection in high-risk groups such as the close contacts of leprosy-affected individuals(WHO 2018). The focus on early detection relies on the evidence-based assumption that early detection of leprosy cases would not only reduce its transmission to non-affected individuals but would also reduce the risk of life-long disabilities among the affected. This reduction of risk, however, is most plausible if adequate treatment is delivered to those with confirmed cases of leprosy. As such, the strategy also calls for uniform and short treatment regimens for leprosy which, it is hoped, will increase adherence to the regimen (WHO 2018). By reducing the risk of disabilities and through the targeted campaigns, it is hoped that the strategy will ultimately also reduce the stigma and discrimination associated with leprosy(WHO 2018). A reduction in the stigma and discrimination would decrease the burden of the disease on affected individuals and would increase the effectiveness and acceptability of future prevention and treatment efforts.

Three country programs are highlighted below

India's National Leprosy Control Program

The National Leprosy Eradication Program (NLEP) is sponsored by a Health Scheme of the Ministry of Health and Family Welfare, Govt. of India (NLEP). The Program is headed by the Deputy Director of Health Services (Leprosy) under the administrative control of the Directorate General Health Services Govt. of India. While the NLEP strategies and plans are formulated centrally, the program is implemented by the states and union territories of India (n.i/i). The Program is also supported as partners by the World Health Organization, The International Federation of Anti-leprosy Associations (ILEP), and a few other Non-Governmental Organizations (NGOs). The NLEP was launched in 1955 with the goal of eliminating leprosy as a public health issue. However, it was not until 2012 that special action plans were developed for regions with endemic leprosy. The strategies put forth in the programs include efforts to research, prevent, and treat leprosy(NLEP). In conducting further research, the strategies emphasize the importance of conducting surveys with patients and at-risk populations and improving the monitoring, evaluation, and reporting of public health interventions. In regard to the prevention and treatment of leprosy, the strategies emphasize the importance of increasing access to leprosy services, promotion of early detection and treatment of incident cases, greater attention given to adherence and completion of treatment, prevention of disabilities, and an improvement in availability of and access to rehabilitation services(NLEP).

Brazil's National Leprosy Control Program

In 1990, the government of Brazil, with the support of the International Federation of Anti-Leprosy Associations (ILEP) integrated leprosy into the newly formed the Sistema Unico de

Saude (SUS), or the National Unified Health System, which aimed to prevent, cure, and offer rehabilitative services to all persons at no cost to them(Silva, Lima Neto et al. 2018). A procedural policy was established which aimed to streamline leprosy treatment in the country by demanding that all leprosy cases be referred to SUS. The SUS employed strategies that closely resembled those used by the ILEP. These strategies heavily emphasized the critical roles of early detection, treatment through multi-drug therapy regimens, and the monitoring of close contacts of leprosy patients (Schweickardt and Xerez 2015). However, the SUS programming failed to adequately control Brazil's leprosy epidemic and, as a result, in early 2011, the Health Surveillance Secretariat of the Ministry of Health of Brazil created the General Coordination of Leprosy and Elimination Diseases (CGHDE) (Penna and Penna 2007). This program aimed to supplement existing efforts by the SUS to strengthen the response to a group of diseases, including leprosy. When even this effort failed to adequately address the continued transmission of the disease, in August 2015, Brazil hosted a meeting of the ILEP, which invited country experts and international subject matter experts on leprosy to come together and discuss the problem of continued transmission (Schweickardt and Xerez 2015). The meeting resulted in the attendees agreeing to the importance of prioritizing a goal of zero new cases of leprosy, thus shifting the focus of Brazilian leprosy control initiatives from prevalence control to incidence control.

This drastic shift in outlooks on control initiatives demanded that the country rethink its strategies surrounding leprosy control to better target incidence of the disease. Although early detection of leprosy cases remained a priority, the new strategies which sought to revamp national leprosy control efforts included the prompt treatment of leprosy patients, at least 90%

completion rates of treatment, surveillance of disease incidence, and a focus on addressing the social barriers which exacerbate transmission such as stigma and discrimination against patients(Schweickardt and Xerez 2015).

Japan's National Leprosy Control Program

The passing of the 1996 “Act on Repealing the Leprosy Prevention” allowed for the formal recognition of bioethical violations committed by the government against leprosy patients (Sato 2002). This precedence led the way for leprosy patients in Japan to file a lawsuit against the national government. In the Kumamoto judgment of May 2001, the court ruled that forced isolation was not justifiable(Sato and Narita 2003). The Japanese government investigated the policy and found that it was unconstitutional after the availability of multi-drug therapy(MDT).[JF9] Subsequently, lLeprosy patients forced to live in leprosariaum were compensated by the government for the abuse and violation of their human rights(Sato 2002). Compensation-based programs for persons affected by leprosy included: “Benefits for People Who Were in the Hansen's Disease Sanatoria,” “Reburial Cost for the Diseased in the National Hansen's Disease Sanatoria, etc.” and “Gratuity for People Who Were Not in Hansen's Disease Sanatoria” (Sato and Frantz 2005). Furthermore, Japan's Ministry of Health, Labour and Welfare established a provision for the maintenance of all patients affected by leprosy. The welfare provision covers all medical costs and living expenses.

In an effort to remedy the ethical concerns and violations of human rights inherent in Japan's earlier life-long isolation policy for leprosy patients, in 2008, the government of Japan passed the “Law to Enhance Problem Solving Related to Hansen's.” The law aimed to acknowledge and rectify policy's role in the social and economic discrimination against leprosy patients (Miyasaka

2009). As such, the law dictated that the government would aim to restore the honor of leprosy patients and their families through actions such as the maintenance of a national museum on Hansen's disease and through a commitment to public education on the illness (Aoki 2002). More direct measures to better the lives of patients and their families included a guarantee of the availability of curative treatment protocols and rehabilitation into the broader society. Additionally, new leprosy patients are identified quite early in Japan due to the country's universal healthcare system (Sato and Narita 2003). Under Japanese law, all residents are required to have health insurance coverage and health care is heavily regulated to maintain appropriate cost and quality of care (Mori and Ishii 2017). To ensure that everyone is covered, government has subsidized health care insurance program for those who are covered under their employers or come from low-income households. Patients who cannot afford insurance can have their fee waived after receiving medical care. Furthermore, standard health insurance coverage offered in the country includes screening examinations and infectious disease control (Mori and Ishii 2017). For these reasons, the Japanese system of health care allows for early diagnosis and treatment of leprosy.

According to the Japanese Association of Leprosy, new leprosy patients are treated on an outpatient basis using MDT (Mori and Ishii 2017). The guidelines for treatment and rehabilitation follow WHO's recommended standard treatment protocol . New cases are rare and closely followed, and rehabilitation is part of the country's health insurance system.

Chapter Three: Methods

Literature Review

The first step in the methodology of this paper comprised of conducting an extensive literature review. The materials that were sought for review included the national policies of each of the three countries examined herein, studies regarding the progress of leprosy control initiatives within them, the remaining gaps, and persistent risk factors for leprosy. The databases that were searched were PubMed, GoogleScholar, and Web of Science. The search terms used in each database can be referenced below in Table 1. Due to the nature of this project, one key barrier that was faced in the conduct of this literature review was that of language. Many of the national policies and relevant studies were in the non-English, national languages of the countries examined herein. In cases where the author was not fluent in the language of documentation, GoogleTranslate and other reputable online translation resources were used to make the literature more accessible for review.

Table 1. Search Terminology

Primary Search Term	Expansion Search Term
Leprosy or Hansen’s	Control OR Elimination
Brazil, India or Japan Leprosy	Elimination
Brazil Leprosy	National Control Program
India Leprosy	National Control Program
Japan Leprosy	National Control Program

Leprosy or Hansen’s	Socioeconomic Determinants
Leprosy or Hansen’s	Prevention
Leprosy or Hansen’s	Poverty OR Food security OR Living Conditions OR WASH OR Education OR Gender

Program Comparison

The national leprosy programs of each of the countries were assessed and compared through the Five “E” Approach. The Five-E model was first developed to evaluate the appropriateness and effectiveness of social welfare policy (Mayer, Van Daalen et al. 2004). The proposed model identified five key questions that could result in an overview of a policy or program’s implementation. This paper adapted the approach to identify systematic gaps in national leprosy control programs with a focus on socioeconomic indicators.

Five “E” Approach

1. Effectiveness: How effective is the program?

Overview of a program’s effectiveness is centered around implementation goals. A key indication of a program’s effectiveness is the answer to what extent did the program achieve what it intended to achieve. This point should be supported and strengthened by empirical data on implementation outcomes and accomplishments.

2. Efficiency: How efficient is the program?

Overview of program efficiency is centered around the implementation resources. A key indication of a program’s efficiency is the answer to what extent did the program achieve what it intended to achieve while being economical in time, effort, and finance. This point should be supported and strengthened by empirical data on implementation expenditure.

3. Ethical considerations: Is the program ethically sound?

A program’s ethical considerations and actions before, during, and after implementation are what determines if it is ethically sound . A key indication of a program’s ethical strength is the answer to what extent was the program considerate of both legal and moral implications and impacts of its actions. This point can be supported by the program’s transparency in establishing guidelines and a straightforward approach with target population and communities in which it is operating.

4. Evaluations of alternatives: What does evaluation of potential alternative programs reveal?

This step of the approach is focused on the evaluation of alternative programs with the three previous approaches. Reviewing alternative programs either gives more support to the program being reviewed or allows for the identification of gaps in the program. Both results are essential to the improvement and progress of a program.

5. Establishment of recommendations for positive change: What recommendations can be established for positive change?

The final step of the approach is focused on gathering all the information from the previous steps, assessing the need for amendments, and recognizing which areas of the program need to be re-addressed.

Chapter 4: Results

In using the five-E approach to analyze the national policies of India, Brazil, and Japan, it is important to consider the limitations of analyzing policies after their enactment and from an outsider’s perspective. One such limitation in this case is the consideration of the fourth “E,” evaluations of alternatives. In policy analysis, this step would entail stakeholders and policy-makers debating different policy options that could be adopted. From an outsider’s perspective, understanding the evaluation process that resulted in the adoption of a specific policy presents inherent challenges. Therefore, in this analysis, we have used the fourth “E” as an opportunity to compare the national policy of each respective country to that of the others and to make recommendations to fill gaps in their programs.

India

Effectiveness

One measure through which we can hope to assess the effectiveness of the national leprosy control policy is the prevalence of leprosy within the country. In the case of India, the reduction in prevalence rate has been significant (Muir and Lowe 1933). The prevalence rate of leprosy in India in 1983 was estimated to be approximately 58 cases per every 10,000 people. By 2005, the prevalence rate had dropped to less than 1 case per every 10,000 people. As such, it was in 2005 that India, by WHO’s definition, had eliminated leprosy as a public health problem(Noordeen 2015). The accomplishment of this feat is credited, at least in part, to the implementation of MDT treatment regimens as the national standard of care.

However, despite the success that India has had in reducing their leprosy prevalence rate at a national level, it is important to keep in mind that India continues to account for approximately 60% of new leprosy cases reported around the world(Medley, Crump et al. 2017). Additionally, although India has achieved the standard of < 1 case per 10,000 people at the national scale, disaggregating the statistics by district shows a different story. In fact, by the end of March 2016, 117 districts in India still had prevalence rates above this standard, with rates in some districts being above 10 cases per 10,000 people(Medley, Crump et al. 2017).

Furthermore, it is important to consider that the reduction in prevalence rate may be, in part, due to a lack of adequate reporting and detection protocols. This can be evidenced by the fact that a spike was observed in case incidence with the implementation of the Leprosy Case Detection Campaign (LCDC)(Medley, Crump et al. 2017). Over 34,000 new cases were detected as a result of the LCDC. Lastly, it has been reported that rates of grade two disabilities (G2D), a standard indicator for the success of a leprosy control program, have increased among new cases in India from 1.97% in 2005 to 4.61% by 2015(Noordeen 2015).

Efficiency:

Government data regarding expenditure of the national leprosy control program is not easily available to the public. However, it is known that the program is at least partly supported by the supported by WHO. Consequently, one of the concerns that activists and researchers had was that government was letting go of standards in favor of "progress". Recently, the Supreme Court of India directed the NLEP to be more transparent about their findings.

Ethical considerations:

On paper, India's National Leprosy Eradication Program (NLEP) seems ethically sound; it follows international guidelines, focuses both on prevention and treatment, and leaves some room for municipalities to specifically address social barriers to case detection and treatment. However, a closer look at program implementation brings up important ethical considerations regarding transparency.

Because India receives so much of its leprosy funding from international agencies like WHO, the government faces significant pressure to ensure that the country is meeting WHO elimination targets. This is an ethical concern because it seems that the Indian government is reluctant to make a push for the detection of new cases in an effort to stay on “progress.” Recent evaluation of the NLEP exposed the limitations in the program’s detection capacity and raised questions about its efforts towards active case seeking. In fact, the Supreme Court of India had to step in and direct the government to be more transparent about its detection data and to strengthen leprosy awareness efforts. The ethical implication being that that the NLEP was intentionally or unintentionally not doing enough to secure early diagnosis and treatment of patients.

Establishment of recommendations for positive change:

In establishing recommendations for revitalized leprosy control initiatives, in 2016, India’s Office of the Director General for Leprosy issued a directive in which they highlighted four trends of concern that needed to be addressed (Dimri, Gupta et al. 2016). The first was the continued existence of pockets in which leprosy was highly endemic and easily transmissible. It was from within these highly endemic pockets that the LCDC program had located a majority of new cases. The second trend the directive highlighted was that of leprosy patients in many communities being hidden from detection, for a variety of reasons. Third, it was pointed out that the rate of detection of new leprosy cases in India had remained much the same over the past decade; in 2007, 137,685 new cases of leprosy were detected whereas in 2016, 135,485 new cases of leprosy were detected. Lastly, it was pointed out in the directive, that while other statistical measures of control had remained approximately the same or had decreased, the rates of disability associated with leprosy in new cases had been observed to have risen. It was reasoned that this increase was a result of a delay in diagnosis of new cases. As a response, the

NLEP promoted the creation of area specific plans for case detection in endemic regions along with the launch of leprosy detection and awareness campaigns through community health workers.

Brazil

Effectiveness:

As mentioned before, one measure to assess the effectiveness of the national leprosy control policy is the prevalence of leprosy within the country. In the case of Brazil, the reduction in prevalence rate seems to be significant. The prevalence rate of leprosy in Brazil in 2003 was estimated to be approximately 4.5 cases per every 10,000 people. By 2014, the prevalence rate had dropped to approximately 1.2 cases per every 10,000 people. The accomplishment of this feat is credited to the implementation of MDT treatment regimens as the national standard of care and integration of leprosy treatment into primary healthcare services through the Family Health Program (PSF).

Despite declining incidence rates, the country still struggles to manage the prevalence of leprosy and has yet to meet WHO's definition of leprosy elimination as a public health problem. This is partly due to the high transmission of leprosy in critical parts of the country. According to a 2012 report, 404 of the 692 municipalities in the country were still hyperendemic. Existing research suggests that social factors, like the continued poaching of armadillos and close living contact, might be delaying elimination of the disease in Brazil.

Efficiency:

In 2003, Brazil's Ministry of Health (MOH) began the process of scaling up their leprosy control program due to the continued endemicity of the disease in Brazil. In 2005, the MOH's expenditure on the leprosy control program totalled to be over R$13 million whereas just a year earlier, the total annual expenditure on leprosy control was R$7.7 million. This data shows a drastic increase in costs of the national leprosy control program.

Establishment of recommendations for positive change:

Brazil’s Family Program or Bolsa Família Program (BFP) is a conditional cash transfer program aimed at low SES households with pregnant women and/or mothers with young children. To receive the money, participants must attend education seminars, be up to date with immunization, and access pre- and post-natal care. A recent study found that in regions with increased BFP coverage, the new case detection rate (NCDR) for leprosy was significantly reduced, suggesting a positive impact of welfare policy on leprosy rate. The same study also looked at Brazil’s primary health care program called the Family Health Program (FHP) and discovered that increased coverage of FHP significantly increased NCDR rates in an area. The data collected from this study shows the positive impact that the combination of both welfare and health care programs can have on leprosy incidence.

Cash transfer programs like BFP that positively impact general nutrition, health education, and primary health programs like the FHP that allow for active case detection can be modified within the context of leprosy to act both as protective measures and as early treatment, therefore, positively influencing incidence rate.

Japan

Effectiveness:

The prevalence of leprosy within a country is one measure used to assess the effectiveness of the national leprosy control policy. In the case of Japan, the reduction in prevalence rate has not only been significant but also astonishing . The prevalence rate of leprosy in Japan in the 1900s was estimated to be approximately 7 cases per every 10,000 people. However, from 1995 to 2008, a total of 59 cases of leprosy were reported in the whole country. Since 2003, the new case detection rate (NCDR) for Japan is less than 5 new cases of leprosy per year. As per WHO's definition, the country has eliminated leprosy as a public health concern.

For a country that had a leprosy endemic to decrease their incidence to single digits is amazing. This feat can be credited to three main factors: 1) the 1931 to 1996 Leprosy Prevention Law that isolated all new cases in one of the nation's thirteen leprosariums, 2) the implementation of MDT treatment nationally and 3) the country's comprehensive universal healthcare system.

Efficiency:

Japan's universal health care system has successfully integrated the country's national leprosy control program. The incorporation of the national leprosy control program into the primary health care system makes case management much more efficient. This method of leprosy control and treatment works well for Japan because all residents of the country are already required to have health insurance coverage. Those who are cannot afford coverage are subsidized under the government's welfare system. For these reasons, the Japanese national leprosy control program is more efficient when it comes to early diagnosis and treatment of leprosy.

Ethical considerations:

After a century of enforcing strict isolation of persons affected by leprosy, autochthonous transmission of leprosy in Japan is rare with less than 5 new cases per year. No one would argue the country's success in transforming its leprosy endemic. However, unethical practices and severe human rights violations were key factors of the success. It wasn't until 1996 that forced segregation, considered unnecessary after the advent of MDT, was abolished along with policies of forced sterilization, labor, and punishment. The government eventually apologized and agreed to pay compensation to those who suffered under its discriminatory laws.

The current national leprosy control program is well incorporated in the country's universal health care system and looks to be well thought out in terms of ethical considerations. Under Japanese law, health care is heavily regulated to maintain appropriate cost and quality of care (n.l/m). Patients who cannot afford insurance have their fee waived after receiving medical care.

Establishment of recommendations for positive change:

Given that the majority of Japan's remaining incidence of leprosy originates from rural and often low-socioeconomic status areas off of the mainland, there are key gaps that remain in the leprosy control initiatives employed by the country. Filling these gaps is critical to the successful and complete elimination of incident leprosy cases in Japan. Ensuring that leprosy control initiatives are uniformly available throughout the country, even in rural areas, is a key aspect. The other major step that could allow for a complete elimination is a greater focus on breaking down the socioeconomic barriers to access in non-urban settings.

Chapter 5: Discussion, Recommendations and Conclusion

Case for SES with Leprosy Control Programs

As modern medicine moves forward, breaking boundaries thought unimaginable just a few decades ago, there is an idea that no disease stands a chance against our technological advances. While this idea is important not only because it inspires a new era of researchers but also because it gives hope to suffering patients; it also creates a blind spot that causes gaps in prevention and treatment of diseases. Just as vaccines cannot be truly effective without proper vaccination campaigns and people who choose to vaccinate, diagnosis and treatment alone aren't enough to control the spread of infectious diseases.

There is no denying the importance of clinical care in diagnoses, treatment, and rehabilitation of patients affected by leprosy. However, it is shortsighted of the leprosy control programs examined herein to focus on diagnosis and treatment without much consideration to the social issues that compound a disease as old as time. Even though there is treatment for leprosy, the stigma associated with leprosy ensures that thousands of cases go unreported every year. In turn, delayed diagnosis and treatment lead to severe deformities that can greatly inhibit and even incapacitate the individual.

Insufficient Integration of SES in Brazil & India

Japan's current leprosy control program is the least extensive out of the three programs compared. However, because it is so well integrated within the Ministry of Health, Welfare and Labor, the program addresses major socioeconomic concerns in the transmission, treatment and rehabilitation of leprosy.

On the other hand, the national leprosy programs of Brazil and India have major gaps in the integration of socioeconomic factors in their prevention and treatment plans. Unlike Japan, Brazil and India have not able to manage their leprosy prevalence despite the implementation of MDT treatment and efforts to integrate the programs within the existing health care system.

This could be because the national control programs do not do enough to focus on socioeconomic conditions underlying the cycle of leprosy transmission. leprosy control are beyond hyperendemic countries with large populations and great diversity in ecological background.

Leprosy is a multifaceted disease, and the treatment challenges go beyond the prescription of adequate medication. Complete medical assistance requires a knowledge of the socioeconomic conditions that underlie the cycle of transmission and persistence of infectious diseases in a given society. Effective efforts towards leprosy eradication should also focus on improving housing conditions, sanitation, and education of the population. In addition, the consequences of leprosy-related disabilities must not be underestimated, and programs to rehabilitate patients should be stressed.

Existing SES Gaps in the National Leprosy Programs

1. Lack of SES targeted specific services
2. Existing services are inadequate

Persons affected by leprosy have issues accessing health care, many times they are denied get admission in general hospital wards. When they can access health care, they often find barriers in the system that makes it much harder from them to get care for co-current health issues like hypertension or cataract. There have been reports of mismanagement of leprosy patients by health care providers. In certain cases, untrained hospital staff are tasked with treating cases.

3. Lack of integration

The national leprosy control programs of both Brazil and India countries are working towards integration into the general health and welfare system. Unfortunately, this process is currently insufficient and thus there are major gaps in the services available to persons affected by leprosy. Leprosy patients are not included in nutrition programs that supply food rations to low-income households. In India there were some reported instances where subsidized food rations were denied to persons affected by leprosy because the diseased patients had lost their finger prints.

Recommendations

There is a lot existing evidence to support the association of poverty alleviation and prevalence of infectious diseases in certain regions of the world. Most of the related research is carried out in low or middle-income countries, like India and Brazil, where the burden infectious diseases is compounded by a host of other socioeconomic factors. Given that tuberculosis (TB) and leprosy control programs have some key features in common such as a focus on early diagnosis, clinical treatment, and rehabilitation, leprosy control initiatives can look to strategies employed in TB control to achieve their goals.

Recommendations for socioeconomic support can be broken into two categories. The first focuses on the social aspect that entails knowledge dispersion, and the second focuses on the economic part that entails building resources and financial capital among leprosy-affected individuals, including families of leprosy patients. The recommendations put forth below target gaps in both realms that currently exist in the national leprosy control programs examined herein.

1. Social Protection Initiatives

“Social protection initiatives can enable households to move structurally out of poverty by protecting and building their financial, physical, and human capital assets, thereby contributing to long-term productivity and economic growth”. In terms of infectious diseases, these indicators help households prevent and cope with poverty while decreasing exacerbation of disease status. There are two types of social protection initiatives, ones that provide cash and ones that provide social goods like food, unconditionally or conditionally, to eligible low-income families.

On the other hand, microfinance and micro-loan opportunities can provide complementary support by creating credit opportunities that are sustainable and focused on self-motivated financial development. In the public health field, conditional cash transfer, micro-finance, and micro-loans are often used to target low- socioeconomic households for social and economic development. They typically provide conditional funds with compliance to education, health, and nutrition services.

Recent studies on TB control and cash transfer suggest that cash transfers positively impact poverty and nutrition outcomes in active TB cases. A study done conducted with Brazil’s Family Program (BFP), a conditional cash transfer initiative, on TB found a positive correlation between BFP and the TB treatment completion rate wherein patients enrolled in BFP were more likely to complete their course of treatment. Therefore, the existing literature on the use of this intervention in TB control would support the pilot of social protection initiatives like conditional cash transfers within the framework of leprosy control as well.

2. Scale up and strengthen SES activities

Scaling up SES activities in high risk communities, like leprosy slums, will allow us to focus on control at the local level. It is theorized that if you improve socioeconomic support for persons affected by leprosy you will increase cure rates in patients, increase prevention in their communities, and ultimately produce results that support the control of leprosy country-wide. Scaling up or introducing vocational training programs to address the absence of professional counseling is also a viable option in many of these communities.

Improving the status of WASH through constructing individual toilets and repairing drinking water facilities in leprosy slums would also be deemed a SES activity as access to WASH resources is often dictated by socioeconomic status and power. These barriers to adequate WASH access are especially relevant in the case of leprosy patients as leprosy-affected people are often not adequately organized to raise up to a higher level of leadership due to the social stigma surrounding the disease. There is also evidence that water and soil may be reservoirs for infection, so it is imperative to incorporate WASH improvement strategies in the context of leprosy control.

3. Engage all care providers

As noted already, persons with leprosy have unique difficulties in getting social and welfare services due to stigma and discrimination. Those difficulties can be mediated through work with respective care providers and agencies. For example, many of the government's social and welfare "schemes," or services, don't explicitly include leprosy and thus, persons affected by leprosy are not being able to access services that already exist. To change this status-quo there needs to be additional effort put in by the national leprosy programs to engage with relevant care providers like welfare, disability, and social services so that leprosy is properly defined and can be addressed systematically.

The denial of general health services is a major concern for leprosy patients dealing with other conditions. However, even when patients are able to access health facilities, the services provided therein are often lacking in many of the areas most affected by leprosy. For example, the literature shows a distinct lack of adequate professional and peer counseling services in health facilities.

Conclusions:

Leprosy is perceived as the disease of the poor, not because it discriminates between an individual's social strata, but because often social-economic factors determine who is exposed and subsequently, infected.

The early leprosy control programs of India, Brazil, and Japan focused on segregation of leprosy-affected persons from the rest of society. Until the advent of multi- drug therapy (MDT), isolation facilities served as treatment and rehabilitation centers for patients and as barriers to the spread of the disease to the rest of society. In the past few decades, the leprosy control programs of the three countries have shifted their focus to establishing an integrated healthcare system that allows for the early diagnosis and treatment of persons affected by leprosy. Even with the successes of MDT and national programs, the leprosy incidence rate continues to be a major concern in two of the three countries examined herein. Brazil and India are endemic countries struggling to manage the high burden of leprosy incidence in their populations. An overview of Brazil and India's national leprosy control programs reveals key gaps in the programs' efforts regarding poverty reduction.

In terms of the impact of social factors on leprosy, existing research supports that SES factors are associated with higher leprosy transmission, while stigma and related discrimination are associated with barriers to treatment. Herein, we have proposed three key sets of recommendations that can be employed as strategies to address the socioeconomic risk factors of leprosy. The integration of these recommendations into the national leprosy control programs already in existence in these countries would fill distinct gaps and allow for further progress in achieving leprosy control.

References

Aoki, Y. (2002). "Leprosy prevention law and healthcare professionals in Japan." Int Hist Nurs J **7**(2): 68-74.

> This article considers the issues surrounding leprosy, and focuses on the social stigma and mistreatment associated with the disease. In particular, the history of leprosy patients and leprosy-prevention law in Japan is examined in both a historical and social context. Matters related to infringement of human rights are also considered along with issues for nurses caring for patients with leprosy. Eugenics and its legal approval are then discussed, as is the abolition of the leprosy laws in Japan. Finally, the author argues that problems surrounding this infectious disease are not country-specific; nurses may be ignorant of the number of patients with this debilitating disease worldwide, and of the policies and laws surrounding it.

Braveman, P. and L. Gottlieb (2014). "The social determinants of health: it's time to consider the causes of the causes." Public health reports (Washington, D.C. : 1974) **129 Suppl 2**(Suppl 2): 19-31.

> During the past two decades, the public health community's attention has been drawn increasingly to the social determinants of health (SDH)-the factors apart from medical care that can be influenced by social policies and shape health in powerful ways. We use "medical care" rather than "health care" to refer to clinical services, to avoid potential confusion between "health" and "health care." The World Health Organization's Commission on the Social Determinants of Health has defined SDH as "the conditions in which people are born, grow, live, work and age" and "the fundamental drivers of these conditions." The term "social determinants" often evokes factors such as health-related features of neighborhoods (e.g., walkability, recreational areas, and accessibility of healthful foods), which can influence health-related behaviors. Evidence has accumulated, however, pointing to socioeconomic factors such as income, wealth, and education as the fundamental causes of a wide range of health outcomes. This article broadly reviews some of the knowledge accumulated to date that highlights the importance of social-and particularly socioeconomic-factors in shaping health, and plausible pathways and biological mechanisms that may explain their effects. We also discuss challenges to advancing this knowledge and how they might be overcome.

Dimri, D., et al. (2016). "Leprosy Continues to Occur in Hilly Areas of North India." Dermatology research and practice **2016**: 7153876-7153876.

> Background. The aim of present study was to describe the profile of leprosy patients attending the outpatient department of dermatology in tertiary care hospital in Srinagar, Uttarakhand, North India. Methodology. This descriptive retrospective study. Patient data at the time of diagnosis were retrieved onto a predesigned proforma, which concerned the following variables at the time of registration: age, sex, and residence. Newly registered outpatients leprosy cases between 2009 and 2014 were included in the study. Results. It was found that 65 were multibacillary leprosy cases. Males constituted 62.8% of all leprosy cases. The majority (83.7%) belonged to the age group of 18-60 years. Of the total 48.8% of the new leprosy cases were from the Pauri district. The leprosy incidence rate in this population was 2.71 per 1000 patients. Conclusion. Leprosy still continues to be a communicable disease of concern. The lower incidence in women and children

provokes the need to strengthen contact screening, early case detection, and referral activities in the population to sustain elimination.

Feenstra, S. G., et al. (2013). "Social contact patterns and leprosy disease: a case-control study in Bangladesh." Epidemiol Infect **141**(3): 573-581.

Socioeconomic and culturally defined social contact patterns are expected to be an important determinant in the continuing transmission of Mycobacterium leprae in leprosy-endemic areas. In a case-control study in two districts in Bangladesh, we assessed the association between social contact patterns and the risk of acquiring clinical leprosy. Social contacts of 90 recently diagnosed patients were compared to those of 199 controls. Leprosy was associated with a more intensive social contact pattern in the home [odds ratio (OR) 1.09, 95% confidence interval (CI) 1.00-1.19, P = 0.043] and in the nearby neighbourhood (OR 1.07, 95% CI 1.03-1.11, P = 0.001). Although it is known that M. leprae spreads most easily within households of infected persons, in endemic areas social contacts within the neighbourhood, village or urban ward, also appear to be important for transmission. We advise that disease control measures in leprosy-endemic areas should not be limited to households, but include high-risk groups in the nearby neighbourhood of patients.

Freitas, L. R., et al. (2016). "Trends of main indicators of leprosy in Brazilian municipalities with high risk of leprosy transmission, 2001-2012." BMC Infect Dis **16**: 472.

BACKGROUND: Leprosy incidence has reduced in recent years in Brazil, although the disease still persists as a public health problem in some regions. To investigate the trends of selected leprosy indicators in Brazilian municipalities with high risk of transmission is essential to provide effective control of the disease, yet this area has not been investigated. METHODS: This is an ecological time-series study with multiple groups using Notifiable Diseases Information System (SINAN) data. All 692 municipalities of the states of Mato Grosso, Tocantins, Rondonia, Para and Maranhao were included. The incidence rates of leprosy were calculated, as well as incidence rates in children under 15 years per 100,000 inhabitants and rates of new cases presenting grade-2 disabilities per 100,000 inhabitants. Joinpoint Regression was used to analyse the time trends of the different indicators studied. The spatial distribution of temporal variations of the indicators in the period was presented. RESULTS: Between 2001 and 2012, 176,929 leprosy cases were notified in the area studied, this being equivalent to 34.6 % of total cases in Brazil. In the aggregate of municipalities, there was a reduction in incidence rate of leprosy from 89.10 to 56.98 new cases per 100,000 inhabitants between 2001 and 2012, with a significant reduction between 2003 and 2012 (APC: - 6.2 %, 95 % CI: -7.2 % to -5.2 %). The incidence rate in <15 years also reduced significantly between 2003 and 2012 (APC: -5.6 %; 95 % CI: -7.2 % to -4.1 %). The rate of new cases with grade 2 disability remained stable between 2001 and 2012 (APC: -1.3 %; 95 % CI: -2.6 % to 0.1 %). CONCLUSION: Despite the reduction in the leprosy incidence rate, strategies for controlling this disease need to be enhanced to enable early case detection, especially in hyperendemic municipalities, in order to prevent disability.

Kerr-Pontes, L. R., et al. (2006). "Socioeconomic, environmental, and behavioural risk factors for leprosy in North-east Brazil: results of a case-control study." Int J Epidemiol **35**(4): 994-1000.

> BACKGROUND: Brazil reports almost 80% of all leprosy cases in the Americas. This study aimed to identify socioeconomic, environmental, and behavioural factors associated with risk of leprosy occurrence in the endemic North-eastern region. METHODS: A case-control study in four municipalities. CASES: cases of leprosy diagnosed in the previous 2 years, with no other known, current, or past case of leprosy in the household or in the neighbourhood. CONTROLS: individuals presenting for reasons other than skin problems to the health unit where the case was diagnosed and who lived in the same municipality as the case with whom it was matched. For each case four controls were selected. A semi-structured questionnaire was used to collect demographic, socioeconomic, environmental, and behavioural data. A multivariate hierarchical analysis was performed according to a previously defined framework. RESULTS: 226 cases and 857 controls were examined. Low education level, ever having experienced food shortage, bathing weekly in open water bodies (creek, river and/or lake) 10 years previously, and a low frequency of changing bed linen or hammock (>or=biweekly) currently were all significantly associated with leprosy. Having a BCG vaccination scar was found to be a highly significant protective factor. CONCLUSIONS: Except for BCG vaccination, variables that remained significant in the hierarchical analysis are cultural or linked to poverty. They may act on different levels of the transmission of Mycobacterium leprae and/or the progress from infection to disease. These findings give credit to the hypothesis that person-to-person is not the only form of M. leprae transmission, and that indirect transmission might occur, and other reservoirs should exist outside the human body.

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Mori, S. and N. Ishii (2017). "[A Study on the Entering and Out-going Trends at Japan's National Hansen's Disease Sanatoriums]." Nihon Hansenbyo Gakkai Zasshi **86**(1): 69-90.

> A Hansen's disease (HD) policy began in Japan with the enactment of the No. 11 Act on Leprosy (1907 law No. 11), which was the first leprosy prevention law in Japan in 1907. Results of the law included the enforcement of regulations of the stated law and the establishment of Prefectural Allied (National) HD Sanatoriums in 1909. This policy continued until the "leprosy prevention law" abolition in 1996, and about 35,000 people were placed in isolation; however, its entering and out-going trends are not clear yet. The purpose of this research is to clarify the actual condition of the Japanese HD policy. We added up the number of individuals entering and leaving the sanatorium from 1909 to 2010. This information was collected from annual reports and the internal material from

each national sanatorium. In the results, the number of general residents (new, re-entering, transferring from other sanatoriums) and the number of general out-going persons (transferring to another sanatorium, formal discharge, informal discharge including escape and wrong diagnosis, and others) were all totaled as the running number during the 102 year span, in addition to being added to the deaths. The results show that the number of general residents was 56,575 people and the number of general out-going persons was 54,047 people (death: 25,200 people; change of sanatorium: 4,350 people; formal discharge: 7,124 people; informal discharge including escape: 12,378 people; wrong diagnosis: 310 people; others: 4,685 people). Based on the details of each leprosy prevention law, the results for the first "1907 law No. 11" show that the number of general residents was 12,673 people and the number of general out-going persons was 9,070 people. The "1931 leprosy prevention law" results show that the number of general residents was 31,232 people and the number of general out-going persons was 23,354 people. The "1953 leprosy prevention law" results show that the number of general inmates was 12,098 people and the number of general out-going persons was 18,159 people. The "1996 law about repeal of leprosy prevention law" results show that the number of general residents was 572 people and the number of general out-going persons was 3,464 people. We can clarify the number of general residents and the number of general out-going persons in the National HD Sanatoriums in Japan.

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Nobre, M. L., et al. (2017). "Multibacillary leprosy by population groups in Brazil: Lessons from an observational study." PLoS Negl Trop Dis **11**(2): e0005364.

BACKGROUND: Leprosy remains an important public health problem in Brazil where 28,761 new cases were diagnosed in 2015, the second highest number of new cases detected globally. The disease is caused by Mycobacterium leprae, a pathogen spread by patients with multibacillary (MB) leprosy. This study was designed to identify population groups most at risk for MB disease in Brazil, contributing to new ideas for early diagnosis and leprosy control. METHODS: A national databank of cases reported in Brazil (2001-2013) was used to evaluate epidemiological characteristics of MB leprosy. Additionally, the databank of a leprosy reference center was used to determine factors associated with higher bacillary loads. RESULTS: A total of 541,090 cases were analyzed. New case detection rates (NCDRs) increased with age, especially for men with MB leprosy, reaching 44.8 new cases/100,000 population in 65-69 year olds. Males and subjects older than 59 years had twice the odds of MB leprosy than females and younger cases (OR = 2.36, CI95% = 2.33-2.38; OR = 1.99, CI95% = 1.96-2.02, respectively). Bacillary load was higher in male and in patients aged 20-39 and 40-59 years compared to females and other age groups. From 2003 to 2013, there was a progressive reduction in annual NCDRs and an increase in the percentage of MB cases and of elderly patients in Brazil. These data suggest reduction of leprosy transmission in the country. CONCLUSION: Public health policies for leprosy control in endemic areas in Brazil should include activities especially addressed to men and to the elderly in order to further reduce M. leprae transmission.

Noordeen, S. K. (2015). "Eliminating Leprosy in India--Is it a Dream?" Indian J Lepr **87**(2): 75-77.

In recent years there have been considerable discussions on the current leprosy situation in India and the status of the country's attempts to eliminate or eradicate the disease. In this connection it is very important to analyze the background and various developments relevant to leprosy elimination in India.

Penna, M. L. and G. O. Penna (2007). "Trend of case detection and leprosy elimination in Brazil." Trop Med Int Health **12**(5): 647-650.

Only six countries did not meet the leprosy elimination target during 2005, amongst them Brazil. In 2006, the Brazilian Ministry of Health announced a reduction of the detection rate of 24% or 10 900 cases from 2004 to 2005. A negative binomial parabolic regression model was adjusted to the detection rate historical series from 1980 to 2004, in order to predict the 2005 detection rate and its 95% confidence interval. This analysis showed that the number of new leprosy cases for 2005 could not be predicted from the previous behaviour of the data what calls for an epidemiological or operational explanation hypothesis. The hypothesis that this drop in detected case number is due to operational change, as a reduction in diagnosis or a modification in the reporting routine, is more likely. Recent change in prevalence case definition turned the prevalence ratio a function of only one variable, the detection rate, as the duration of the diagnosed disease became fixed. In the early nineties, based on epidemiological data evaluation, the BMoH recognized the impossibility of reaching the elimination goal, but it committed to seek leprosy control. This position changed after some years. Leprosy Elimination is a strategy supported by the national and international public opinion. As a one for all recipe, it may cause unwanted effects for it is not flexible enough to deal with different epidemiological behaviours and public health traditions.

Pescarini, J. M., et al. (2018). "Socioeconomic risk markers of leprosy in high-burden countries: A systematic review and meta-analysis." PLoS Negl Trop Dis **12**(7): e0006622.

Over 200,000 new cases of leprosy are detected each year, of which approximately 7% are associated with grade-2 disabilities (G2Ds). For achieving leprosy elimination, one of the main challenges will be targeting higher risk groups within endemic communities. Nevertheless, the socioeconomic risk markers of leprosy remain poorly understood. To address this gap we systematically reviewed MEDLINE/PubMed, Embase, LILACS and Web of Science for original articles investigating the social determinants of leprosy in countries with > 1000 cases/year in at least five years between 2006 and 2016. Cohort, case-control, cross-sectional, and ecological studies were eligible for inclusion; qualitative studies, case reports, and reviews were excluded. Out of 1,534 non-duplicate records, 96 full-text articles were reviewed, and 39 met inclusion criteria. 17 were included in random-effects meta-analyses for sex, occupation, food shortage, household contact, crowding, and lack of clean (i.e., treated) water. The majority of studies were conducted in Brazil, India, or Bangladesh while none were undertaken in low-income countries. Descriptive synthesis indicated that increased age, poor sanitary and

socioeconomic conditions, lower level of education, and food-insecurity are risk markers for leprosy. Additionally, in pooled estimates, leprosy was associated with being male (RR = 1.33, 95% CI = 1.06-1.67), performing manual labor (RR = 2.15, 95% CI = 0.97-4.74), suffering from food shortage in the past (RR = 1.39, 95% CI = 1.05-1.85), being a household contact of a leprosy patient (RR = 3.40, 95% CI = 2.24-5.18), and living in a crowded household (>/=5 per household) (RR = 1.38, 95% CI = 1.14-1.67). Lack of clean water did not appear to be a risk marker of leprosy (RR = 0.94, 95% CI = 0.65-1.35). Additionally, ecological studies provided evidence that lower inequality, better human development, increased healthcare coverage, and cash transfer programs are linked with lower leprosy risks. These findings point to a consistent relationship between leprosy and unfavorable economic circumstances and, thereby, underscore the pressing need of leprosy control policies to target socially vulnerable groups in high-burden countries.

Sato, H. (2002). "Abolition of Leprosy Isolation Policy in Japan." Policy Studies Journal **30**(1): 29-46.

The termination of a policy is often considered an important step for correcting existing policies and allocating resources efficiently. Scientific advances, for example, may make the existing policy obsolete and unjustifiable. Delay in terminating a flawed policy may result in increasing its harm. In many cases, however, it is suggested that inertia and other obstacles must be overcome before a termination can be accomplished. Health policy is no exception to these findings. The isolation of leprosy patients, a practice introduced early in this century, was maintained in Japan even after it proved scientifically unnecessary. It was only after a few decades of inertia and political struggles that the policy was abolished. As can be seen in previous studies in the other domains, a set of obstacles, such as intellectual reluctance, opposition of vested interests, and bias in expert opinions, existed, and hampered the timely termination of the isolation policy. Over a long time, policy adaptation was gradually made in practice through the loose administration of policy. It was only by the leadership of a skillful terminator that the issue was finally brought to the forefront, consensus achieved among key actors, and the policy abolished.

Sato, H. and J. E. Frantz (2005). "Termination of the leprosy isolation policy in the US and Japan : Science, policy changes, and the garbage can model." BMC International Health and Human Rights **5**(1): 3.

In both the US and Japan, the patient isolation policy for leprosy /Hansen's disease (HD) was preserved along with the isolation facilities, long after it had been proven to be scientifically unnecessary. This delayed policy termination caused a deprivation of civil liberties of the involuntarily confined patients, the fostering of social stigmas attached to the disease, and an inefficient use of health resources. This article seeks to elucidate the political process which hindered timely policy changes congruent with scientific advances.

Sato, H. and M. Narita (2003). "Politics of leprosy segregation in Japan: the emergence, transformation and abolition of the patient segregation policy." Soc Sci Med **56**(12): 2529-2539.

The segregation of leprosy patients, a practice introduced early in the 20th century, was maintained in Japan after World War II. It locked in the viability of subsequent policy choices, and patients' isolation was sustained long after it was proven to be scientifically unnecessary. For leprologists and leprosarium directors, there was little opportunity to conceptualize and test the epidemiological validity and effectiveness of outpatient services as alternatives to the existing policy, since most of the patients were already hospitalized. Since leprosy was no longer a threat to the general public, bureaucratic officials, as well as legislators, lacked strong incentives to reformulate the overall policy. Within the Ministry of Health and Welfare, daily tasks were largely transferred to the section for leprosarium management, and the search for other options lost importance. For patients, long institutionalization elevated their dependency on life in leprosaria. These conditions must be emphasized as policy legacies, the results of past policies, since they posed obstacles to effective policy innovation in accordance with changing scientific knowledge. To make policies reflective of scientific knowledge, it is essential to understand and foresee the effect of policy legacy, when introducing and appraising public health policies.

Schweickardt, J. C. and L. M. Xerez (2015). "Hansen's disease in the state of Amazonas: policy and institutional treatment of a disease." Hist Cienc Saude Manguinhos **22**(4): 1141-1156.

This article discusses the historical aspects of the policies for controlling Hansen's disease in the state of Amazonas from the second half of the nineteenth century until the dismantling of this model in 1978. We present the historical changes in the local institutions and policies, and their relationship with national policies. The history and policies related to Hansen's disease in the state of Amazonas are analyzed through the following institutions: Umirisal, the Oswaldo Cruz Dispensary, the Paricatuba Leprosarium, the Antonio Aleixo Colony, and the Gustavo Capanema Preventorium. We seek to show that these institutions cared for the people who suffered from Hansen's disease and those related to them, and were also responsible for carrying out the policies for fighting and controlling the disease.

Silva, A. R. D., et al. (2018). "Factors associated with leprosy in a municipality of the Pre-Amazon region, state of Maranhao, Brazil." Rev Soc Bras Med Trop **51**(6): 789-794.

INTRODUCTION: The Integrated Program of Leprosy Control was initiated in the municipality of Buriticupu, Maranhao, Brazil, an area considered hyperendemic for leprosy in 2003. It aims at assessing the clinical and epidemiological characteristics of the disease to reduce the detection rate of new cases until 2015. Here, we present the evolution of the indicators of leprosy within the period from 2003 to 2015. METHODS: We conducted a descriptive analytical study based on the active search for and voluntary referral of cases of leprosy. The detection rate of new cases was analyzed over time. We included individuals diagnosed with leprosy between January 2003 and December 2015. The association between categorical variables was assessed using the chi-square test of independence, considering a level of significance of 5%. When the association was significant, the detection rate (with a confidence interval of 95%) was calculated. RESULTS: Overall, 879 new leprosy cases were detected; the majority of the affected individuals were men (65.9%). Multibacillary leprosy was the most common type of the disease, according to the operational classification (55.5%); it showed the strongest association with an age >/=60 years. We also detected an association between the male sex and both, lepromatous and multibacillary leprosy. The detection rate reduced from

211.09/100,000 population in 2003 to 50.26/100,000 population in 2015. CONCLUSIONS: We found an improvement in leprosy control, with a reduction in the detection rate and the absolute number of cases. Strengthening of disease control measures should be prioritized to eliminate leprosy as a public health concern in this municipality.

WHO (2018). "The Guidelines for the Diagnosis, Treatment and Prevention of Leprosy." from https://apps.who.int/iris/handle/10665/274127.