

Leprosy in Northeastern Brazil: An Analysis of Populations and Interventions

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### **Problem Statement**

Historically, leprosy has posed a significant global burden. Records dating back to biblical times convey not only the physical burden of the disease, but also the stigma associated with having leprosy. Since the introduction of multi drug therapy in the 1980s, the burden of leprosy worldwide has decreased, but 105 endemic countries still exist (Secco et al., 2017). In 2015, 210,758 new cases were diagnosed (Fischer, 2017). The World Health Organization has created the Global Leprosy Strategy, a four year plan from 2016-2020 that includes goals, targets, strategies, and plans to stimulate progress toward a leprosy free world (WHO, 2016) . The plan emphasizes the importance of early case detection and uniform treatment, strengthening government programs, and stopping prejudice against people with leprosy. While the number of new leprosy cases annually is small relative to other neglected tropical diseases, 81% of the new cases were reported in India, Brazil, and Indonesia (WHO, 2016). 61% of the newly diagnosed patients worldwide in 2014 were multibacillary cases, meaning there is a larger burden of bacteria, and 64% of the new cases were men (WHO, 2016). Brazil has the second highest incidence of leprosy, accounting for 13% of new cases globally (Nogueira et al., 2017). Leprosy is considered to be eliminated in Brazil's southern states because the annual incidence is below 1 new case per 10,000 people (incidence = 0.16/10,000) (Nazario et al., 2017). However, Brazil's northern states are considered highly endemic. Socioeconomic inequality, education, and accessibility to health services are considered significant predictors for high incidence rates in the northern states (Kerr-Pontes, Montenegro, Barreto, Werneck, & Feldmeier, 2004). Additionally, incidence is higher in rural areas than urban areas, however, patterns of migration and urbanization in the northern states mean that urban areas are increasingly at risk (Kerr-Pontes et al., 2004). This paper will explore leprosy in communities in northeastern Brazil,

particularly its impact among individuals of low socioeconomic status due to the increased prevalence and incidence of leprosy in northeastern Brazil and the recognition of low socioeconomic status as a risk factor for leprosy.

### **Scientific Understanding**

In recent years there has not been great improvement in leprosy control. In the first quarter of 2012, there was a registered prevalence of 181,941 cases of leprosy worldwide with 34,801 of these cases occurring in the Americas. At the end of 2011, there were 219,075 total new cases (WHO, 2012). In 2015, there were still 210,758 new cases (Fischer, 2017) showing stagnancy in progress toward eliminating leprosy worldwide.

All cases of leprosy are caused by the bacterium *M. leprae*, but reactions vary depending on the individual (Ribeiro-Rodrigues, 2012). 95% of the global population is not susceptible to the disease and most of the remaining 5% can successfully fight off infection. However, approximately 1% of people will develop the disease (Massone & Nunzi, 2012). In endemic areas a significant portion of the population may be infected with the disease, but only 5-10% will manifest the disease while some spontaneously clear it (Fischer, 2017).

Transmission of leprosy comes predominantly from prolonged contact with an infected individual through droplets and mucosa in the upper airways. Other routes of transmission are due to infected needles used for vaccines and tattoos (Massone & Nunzi, 2012). The bacteria can survive without direct UV contact for up to six weeks in soil, which increases transmission potential (Massone & Nunzi, 2012). Reactions vary due to the upgrading and downgrading of the disease in severity: borderline forms of leprosy to tuberculoid leprosy depending on the individual (Fischer, 2017).

The transmission and development of leprosy is not fully understood, but it is believed that an individual's primary reaction is the main determinant of how the disease will progress in their body. Factors that affect progression are the natural immune response, a low bacterial load, and a failure of the disease to clinically manifest (Ribeiro-Rodrigues, 2012). Overall leprosy most commonly affects the peripheral nervous system with manifestations in the skin, bones, joints, mucous membranes, eyes, testes, muscles, and adrenals (Talhari, Talhari, & Penna, 2015). All forms of leprosy can be associated with the loss of fingers, ulcers, malformation of hands, and a loss of sensation, particularly thermal sensation (Talhari et al., 2015).

In 1953 at the Madrid Congress, the clinical parameters of leprosy were distinguished from one another as (1) indeterminate leprosy, (2) tuberculoid leprosy, (3) borderline leprosy, (4) lepromatous leprosy (Talhari et al., 2015).

Indeterminate leprosy is the disease classification before it is clear how the disease will develop. It can last for up to five years and it is very important to diagnose early so that the disease does not develop further. At this stage it is not contagious and will not result in permanent nerve damage; however, it can potentially progress into a more serious form (Fischer, 2017). Towards the end of this stage there may begin to be neurological manifestations like decreased sweating; however, an individual will still experience pain sensitivity (Fischer, 2017). If there are no lesions and it goes untreated it will develop into tuberculoid or borderline tuberculoid leprosy. If there are lesions it will likely develop into borderline-borderline, borderline lepromatous, or lepromatous leprosy, the more severe forms of leprosy (Talhari et al., 2015). The following outlines the different types of leprosy beginning with tuberculoid leprosy (TL) on one pole with very little associated bacterium (paucibacillary), and lepromatous leprosy (LL) at the other pole with a high bacterial load (multibacillary).

Tuberculoid Leprosy	Borderline Tuberculoid Leprosy	Borderline-Borderline	Borderline Lepromatous	Lepromatous Leprosy
-Tuberculoid leprosy results in decreased sensitivity and difficulty in distinguishing heat sensations (Fischer, 2017)	-Affects sensory and motor nerves and causes granulomas to form (Fischer, 2017)	-Affects more of the body, but is only minimally associated with hair loss and a decrease in sweating (Fischer, 2017)	-Affects large areas and many nerves (Fischer, 2017) -Not characterized by granulomas, but has a lot of clustered mycobacterium (Fischer, 2017)	-Can lead to blindness when there is ocular infection -Can affect the kidneys, liver, and bone marrow. -Up to 10% of affected will go blind -Bacterial mass in a person can weigh up to several kilograms (Fischer, 2017)

When leprosy reactions occur they can be life threatening and 30% of patients will develop the severe reactions mentioned previously (Fischer, 2017). The least aggressive forms cause swelling, but the most aggressive forms can cause extreme disability (Fischer, 2017). As with most infectious disease, treatment is very important for stopping transmission. It is necessary to use multi-drug therapy because drug resistance has become a large issue with leprosy and mono-drug therapy is entirely useless (Fischer, 2017). Even with treatment, leprosy patients can still experience dramatic disability and need physical therapy or other palliative care (Fischer, 2017).

### **Affected Populations**

Leprosy is endemic in 105 countries and 81% of the new cases in 2016 were reported in India, Brazil, and Indonesia (Secco et al., 2017; WHO, 2016). In 2015, 210,758 new cases were diagnosed globally: 127,326 (60%) in India; 26,395 (13%) in Brazil; and 17,202 (8%) in Indonesia (WHO, 2016). Leprosy is unevenly distributed between countries around the world and also between regions within countries themselves. A major factor contributing to the high

prevalence of leprosy in particular countries and regions is socioeconomic status, which explains why poor areas of India, Brazil, and Indonesia stand out in terms of their burden of leprosy (Blok, De Vlas, & Richardus, 2015). As a result of the regional prevalence, whole countries, such as India, Brazil, and Indonesia are on track for the WHO's leprosy elimination target of less than 10 new cases per 100,000; however, attention to specific poor regions within each country reveals that the incidence of certain areas are still 2-7 times higher than the national average (Blok et al., 2015). After achieving the international leprosy elimination target, it is imperative that countries still focus public health efforts to reduce leprosy transmission in their highly endemic regions (Blok et al., 2015).

Women are a particularly vulnerable population to leprosy. 36% of the newly diagnosed cases of leprosy around the world in 2014 were women (WHO, 2016). A study conducted in two Indian states examined the unequal impact of leprosy between men and women. The study concluded that while the incidence of leprosy for women is lower than that of men, women experience more severe consequences as a result of the disease. In India, women with leprosy experience more social stress and stigma than do men. Women are rejected from their domestic environments in which they usually receive social support and as a result, they suffer whereas, men typically have more access to information surrounding leprosy diagnosis and play a larger role in health promotion than women do (Vlassoff, Khot, & Rao, 1996).

Sarkar and Pradhan (2016) conducted a review on leprosy among women in India, particularly on the difference of prevalence and clinical features that occur in women as compared to men. The report suggested that women in developing countries typically delay seeking out health care more than do men, one reason for this is their financial dependence on men. Additionally, pathology of leprosy occurs later in the course of the disease in women than it

does in men. Both of these factors result in a higher likelihood of women developing more severe physical deformities than men. The report emphasized that women have a high likelihood of having domestic roles and therefore, have significant contact with children and other members of their families which increases the likelihood of leprosy transmission. Underreporting of leprosy cases among women is highly suspected due to their decreased mobility and higher illiteracy rates compared to men (Sarkar & Pradhan, 2016).

Children under the age of 15 are also a uniquely vulnerable population due to their dependence on others, particularly their caregivers. Globally in 2014, 8.8% (18,869) of the new cases of leprosy were children (WHO 2016). Pinto, Waccholz, da Silva, and Masuda (2017) conducted a retrospective study using information at a Brazilian reference center to examine leprosy among children in Brazil between 2004 and 2012. Reference centers are specialized outpatient clinics that are used for the diagnosis of specific diseases in Brazil (Barbieri et al., 2016). The report from their research concluded that it is very likely that children with leprosy contracted leprosy from people who are undiagnosed themselves. Children are very susceptible to contract leprosy because of their sustained contact with caregivers, but if children with leprosy can get their condition diagnosed and treated early enough in the course of the disease they are less likely to develop physical deformities (Pinto, Wachholz, da Silva, & Masuda, 2017). Given that children rarely seek medical care themselves, the researchers emphasized the importance of focusing on diagnosing children in order to decrease further transmission and morbidity associated with leprosy (Pinto, Wachholz, da Silva, & Masuda, 2017).

Children who contract leprosy typically experience pathology during young adulthood due to the long incubation period of the disease (Lustosa et al., 2011). The incidence of leprosy among children is a strong indicator for the rates of transmission of leprosy in particular

communities. Therefore, a focus on improving case detection rates of leprosy among children not only decreases the likelihood of children developing deformities due to leprosy, but it also provides critical information on the status of leprosy and the effectiveness of interventions in communities around the world (WHO 2016).

People with a low quality of life, particularly a low socioeconomic status experience a disproportionately heavy burden of leprosy. An observational study in Brazil used a questionnaire to identify the determinants of poor quality of life among people with leprosy (Lustosa et al., 2011). The report emphasized a negative cycle of poverty related to the burden of leprosy. People with less education in turn earn a lower income which results in inadequate living conditions that promote leprosy transmission (Lustosa et al., 2011). People who contract leprosy and fail to seek out healthcare services are likely to develop deformities that then prevent them from working and earning an adequate income (Lustosa et al., 2011). As a result, poor quality of life and stigma associated with leprosy is perpetuated, resulting in an overall higher burden of disease among low socioeconomic status populations (Lustosa et al., 2011). Another ecological study in northeast Brazil collected data on environmental conditions to determine their effect on leprosy incidence. This study also found that lower socioeconomic status and levels of education as well as poor hygiene practices were significantly related to a higher incidence of leprosy (Kerr-Pontes et al., 2004). The poor environmental conditions present in northeastern Brazil put low income populations in a vulnerable position.

### **Specific Population**

Northeast Brazil, the poorest region in the country, experiences much higher rates of newly diagnosed cases of leprosy than southern Brazil, the richest region in the country. This paper will focus on the burden of leprosy among people living in northeastern Brazil because of

their low socioeconomic status. Half of the population in northeast Brazil lives in poverty and large inequalities exist between the rich and poor with the top 1% earning an income equal to the bottom 50% of people living in the region (Kerr-Pontes et al., 2004). This economic inequality is evident throughout the history of northeastern Brazil.

The history of northeastern Brazil is plagued by financial issues, government inaction, and a difficult climate as compared to the southern region (Kutcher & Scandizzo, 1981). Northeast Brazil was the first region to be colonized by the Portuguese in the 1500s. The profitable exportation of sugarcane and Brazilwood from northeast Brazil provided the financial resources necessary for settlement to move inland into southern Brazil (Kutcher & Scandizzo, 1981). In the 1700s, the sugarcane industry moved to southern Brazil due to the discovery of gold and other precious minerals, useful harbors for trade, and more fertile soil than the northeast had to offer (Kutcher & Scandizzo, 1981). As industry and wealth moved to the south, the north was left with an inefficient political, social, and economic system based on a sugarcane industry that no longer existed. In 1762, the capital was moved from Bahia in the north to Rio in the south which further isolated northeast Brazil geographically, socially, politically, and economically (Kutcher & Scandizzo, 1981). In 1889, the Northeast region was split into many smaller states which allowed the south to have comparatively more political power in the government. Since the 1880s, common droughts have threatened the water and food security of people living in the region. The government has made attempts to intervene, but with limited success due to a continued focus on the more prosperous south (Kutcher & Scandizzo, 1981). The history of northeastern Brazil informs the ongoing financial inequality between the northern and southern regions and subsequent increased prevalence of poverty and leprosy seen in the northeastern region.

Low socioeconomic status affects the ability of people to access health services. Brazil provides healthcare services in a two tier system that includes private and public healthcare (Alves & Timmins, 2001). For those who have health care provided by their employer or who can afford private healthcare, services are readily available and of a high quality. The rest of the population is reliant on the government provided health care program, Sistema Único de Saúde (SUS), which has been argued to be of a low quality and overburdened (Alves & Timmins, 2001). Due to the low socioeconomic status of Brazilians in the northeast region, they are reliant on the government run public system for healthcare services. The long wait times and low quality health services have prevented early diagnosis of leprosy because people are not able to access healthcare services in a timely manner (Alves & Timmins, 2001). However, in 1994, Brazil instituted a component of the SUS called the Family Health Plan (FHP) that aims to address issues in the SUS (Nery et al., 2014). The FHP focuses on providing primary health care through a community based approach that assigns family care teams to households. Family care teams include a physician, a nurse, a nurse assistant, and four to six full-time community health agents (Macinko and Harris, 2015). While each family care team can be responsible for providing care to up to 1,000 households, each community health agent is assigned about 150 households so that they can visit each of their assigned households about once per month (Macinko and Harris, 2015). The FHP has experienced rapid expansion due to its success. In 1998, 2,000 health care teams existed providing services to about 4% of the Brazilian population. In 2014, the program had 39,000 health care teams that served 62% of the population (Macinko and Harris, 2015). In addition, since the mid 2000s the implementation of the SUS as a whole has focused on efficiency and quality issues by establishing and improving regional healthcare networks, like the FHP (Gragnolati, 2013), which would not have been accounted for in Alves

and Timmins (2001) review. Northeast Brazilians have a high burden of leprosy due to their low socioeconomic status and historical lack of access to health services, although the Brazilian government is improving healthcare delivery through the SUS and FHP. In a study that tracked the infant mortality rate, a key determinant of population health, in Brazil from 1996-2004, results showed that the infant mortality rate decreased by up to 22% with the highest level of FHP coverage (Aquino, de Oliveira, & Barreto, 2009).

Like other leprosy endemic areas, social stigma resulting from a lack of understanding and fear of the disease is common in Brazil. An interview project with 16 Brazilian males and 11 Brazilian females illustrates that although respondents feel like stigma of leprosy patients is improving, it still exists in Brazil today (Sillo et al., 2016). A 21 year old woman diagnosed in 2013 states, "if I go in my mother-in-law's house and she offers water and I drink ... She throws the glass away. She prefers to throw it away than wash it, understand? They have a huge fear of catching [leprosy]" (Sillo et al., 2016). The exact mode of transmission of the disease is unclear which contributes to people's fear of contracting leprosy.

Leprosy mainly affects working populations due to the interference of physical deformities and stigma (Lustosa et al., 2011). A female respondent said, "The director of the school wanted me to ask [for] resignation. I worked there for many years. Yes, [they] came to me saying: 'whore, bitch'. I became a whore, a bitch, a thief, a rotten leg. I didn't believe in prejudice until I faced it" (Sillo et al., 2016). Discrimination and stigmatization of people with leprosy can lead them to be fired from their jobs. Without the ability to get a job, people with leprosy and their families who are reliant on them are forced to live a life of poverty. Individuals who have visible disabilities experience even more stigmatization (Lustosa et al., 2011). Due to social stigma there is a common tendency of people with leprosy to conceal their condition. When

people conceal their condition, diagnosis and treatment can be delayed increasing the risk for physical deformities. Those physical injuries then impact the working capacity of individuals with leprosy, which most strongly impacts poor people (Lustosa et al., 2011).

Another factor contributing to the problem of leprosy in northeastern Brazil is the heavy in and out migration of people in the region. The poor economic prospects within the region draw people out of high endemic areas to low endemic areas in search of work in neighboring regions. The migration is also from rural to urban areas because of urbanization, which creates severe socioeconomic inequality and the promise of jobs (Kerr-Pontes et al., 2004). Although railroads are no longer in operation in much of northeastern Brazil, areas with railroad stops have higher rates of leprosy due to the usage of railroads for migration and the jobs the railroad created (Kerr-Pontes et al., 2004). Migration is also determined by social networks with many migrants moving to areas where they have close family, friends, or existing relationships. Due to the relationships, migrants move into houses with the people in the new region leading to increased transmission of leprosy (Murto et al., 2013). The trend of uncontrolled urbanization in which many people migrate to poor neighborhoods outside of a city is very common in northeast Brazil. These rapidly forming low socioeconomic status communities are at high risk of leprosy transmission (Murto et al., 2013). Transmission of leprosy is assumed to occur between people in crowded conditions in which there is inadequate housing and a lack of hygiene (Kerr-Pontes et al., 2004). These conditions are commonly found in areas with a high concentration of people with low socioeconomic status, such as in the urbanized areas of northeast Brazil. The migration of people in endemic areas to other communities is problematic for intervention implementation (Murto et al., 2013). The rapid influx of people into a community means any intervention must be continuous to assure that everyone in the community participates. In addition, interventions

must include components to address stigma, poverty, and health care in order to have an impact on the elimination of leprosy and in improving the lives of those with leprosy in northeastern Brazil.

### Evidence Based Practices to Address Leprosy

#### Effect of the Brazilian Conditional Cash Transfer and Primary Health Care Programs on the New Case Detection Rate of Leprosy

Nery, J. S., Pereira, S. M., Rasella, D., Penna, M. L. F., Aquino, R., Rodrigues, L. C., ... Penna,

G. O. (2014). Effect of the Brazilian Conditional Cash Transfer and Primary Health Care

Programs on the New Case Detection Rate of Leprosy. *PLoS Neglected Tropical*

*Diseases*, 8(11), e3357. <http://doi.org/10.1371/journal.pntd.0003357>

Research Questions/ Objectives/ Study Aims	Setting	Sample	Data Collection Methods and Primary Outcomes
<ul style="list-style-type: none"> <li>-Find out about the effectiveness of the Brazilian conditional cash transfer (Bolsa Familia - BFP) and the primary health care program (Family Health Program - FHP) on the reduction of leprosy new case detection rate</li> <li>-Not much is known about the effectiveness of welfare and primary health care programs on the occurrence of leprosy</li> </ul>	-Municipalities in Brazil	<ul style="list-style-type: none"> <li>-1,358 of 5,570 Brazilian municipalities</li> <li>-Chose municipalities that were high risk because they have high rates of leprosy</li> <li>-Municipalities concentrated in the poorest regions of Brazil, North, Middle West, and Northeast</li> </ul>	<ul style="list-style-type: none"> <li>-Used national databases to obtain data about new cases of leprosy, BFP and FHP coverage, population, and other relevant socio-demographic covariates</li> <li>-Use municipalities as the unit of analysis</li> <li>-Used data from 2004-2011, collected annually</li> <li>-Used Stata Version 10 for data</li> </ul>

Describe the Intervention and Comparison Conditions	Key Study Findings	Study Strengths	Study Limitations
<ul style="list-style-type: none"> <li>-Effect of BFP and FHP coverage at the municipal level on new case detection rate of leprosy</li> <li>-FHP is an expansion of the Brazilian national health care system, the Unified National Health System, and is managed at the municipal level. Multidisciplinary health teams are assigned to defined areas and populations and they control leprosy by supporting early detection and treatment of cases, contact tracing,</li> </ul>	<ul style="list-style-type: none"> <li>-Found that Family Health Program increased new case detection, not because of increased incidence but due to increased self reporting and early detection screening</li> <li>-Also found that Bolsa Familia was associated with decreased rates of detection which they</li> </ul>	<ul style="list-style-type: none"> <li>-Use data from many years (2004-2011) which allows for the tracking of change over time, not just a single year</li> <li>-Use existing programs and infrastructure to control leprosy and evaluate effectiveness instead of creating a new program that could be expensive and inefficient</li> </ul>	<ul style="list-style-type: none"> <li>-Only looks at municipalities that have high rates of leprosy so can't apply to low prevalence areas</li> <li>-Need to evaluate a longer time period to see the effect of the BFP and FHP programs on transmission because leprosy has such a long incubation period</li> <li>-Annual values of</li> </ul>

<p>control of disabilities and other preventive measures</p> <p>-BFP is a cash transfer program for poor families (&gt;\$35-\$70 monthly per capita income). Enrolled families have to meet education and health requirements which reduces extreme poverty, a risk factor for leprosy</p> <p>-There was no control group, but baseline data was collected in 2004</p>	<p>attribute to a reduction in leprosy incidence due to a reduction in poverty and improved living conditions</p> <p>-Combining the FHP and BFP is an effective way to improve diagnosis and control of leprosy while reducing the prevalence of leprosy</p>	<p>-Prevention and control approach, focuses on the social determinants that are risk factors for leprosy such as poverty and access to healthcare</p> <p>-Use data from national surveys and census which allows for a large sample size, 1,358 of 5,570 municipalities in Brazil</p> <p>-Study design clear and detailed</p> <p>-Very good background section that explains both the significance of leprosy in that location and how the BFP and FHP work and how similar programs have been beneficial to HIV reduction</p> <p>-Clear data tables</p> <p>-Possible externality is that effect of the BFP raises overall living condition of municipality, not just the people that are part of the BFP, because of increased money being spent and economic growth which then causes an overall reduction in new leprosy cases because poverty is a risk factor</p>	<p>sociodemographic variables were obtained from linear interpolation and extrapolation from decennial census data, so it is an estimate which could lead to error</p> <p>-In Brazil and Latin America as a whole there has been an improvement in sanitation, education, and economic development which may be confounders for the reduction in new leprosy cases and increased detection - this was not controlled for</p> <p>-Used national data so trusting the accuracy, not doing their own data collection</p>
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### Responding to the challenge of leprosy-related disability and ultra-poverty

Bowers, B., Singh, S., & Kuipers, P. (2014). Responding to the challenge of leprosy-related

disability and ultra-poverty. *Leprosy Review*, 85(3), 141+. Retrieved from

[http://libraries.state.ma.us/login?gwurl=http://go.galegroup.com/ps/i.do?p=AONE&sw=w&u=mlyn\\_m\\_tufts&v=2.1&it=r&id=GALE%7CA501598015&asid=f53f7b8f2c01f0b3](http://libraries.state.ma.us/login?gwurl=http://go.galegroup.com/ps/i.do?p=AONE&sw=w&u=mlyn_m_tufts&v=2.1&it=r&id=GALE%7CA501598015&asid=f53f7b8f2c01f0b31aad96ef81d4b307)

[1aad96ef81d4b307](http://libraries.state.ma.us/login?gwurl=http://go.galegroup.com/ps/i.do?p=AONE&sw=w&u=mlyn_m_tufts&v=2.1&it=r&id=GALE%7CA501598015&asid=f53f7b8f2c01f0b31aad96ef81d4b307)

1aad96ef81d4b307

<b>Research Questions/ Objectives/ Study Aims</b>	<b>Setting</b>	<b>Sample</b>	<b>Data Collection Methods and Primary Outcomes</b>
<ul style="list-style-type: none"> <li>-Figure out ways to reach people with leprosy-related disabilities living below the ultra-poverty with an effective intervention</li> <li>-Create individualized goals and plans with targeted individuals in order to improve their social and financial standing</li> </ul>	-Northwest Bangladesh	<ul style="list-style-type: none"> <li>-2372 people with leprosy-related disabilities in northwest Bangladesh were surveyed</li> <li>-1285 of the surveyed individuals met the criteria of living below the specified ultra-poverty line</li> <li>-Approximately 1100 individuals received services from the intervention</li> <li>-Follow-up data available from 856 in those individuals</li> </ul>	<ul style="list-style-type: none"> <li>-Initial population was surveyed to determine economic status</li> <li>-For the 856 individuals who had a plan implemented a baseline and follow-up poverty assessment was conducted (average of 43 weeks between assessments)</li> </ul>

<b>Describe the Intervention and Comparison Conditions</b>	<b>Key Study Findings</b>	<b>Study Strengths</b>	<b>Study Limitations</b>
<ul style="list-style-type: none"> <li>-Ultra-poverty defined as inability of a person to consume 2100 kcal per day</li> <li>-6 field staff members went through several training programs to survey known individuals with leprosy-related disabilities in a 7000 km<sup>2</sup> area and identify those living below the ultra-poverty line</li> <li>-When an individual living below the ultra-poverty line was identified the staff worked with them, their families, and their communities to create a 3-5 year plan of what social and economic position they would like to be in in 3-5 years time</li> <li>-As a result of the low literacy rate of the target population the plans were based on visuals rather than text</li> <li>-Practical assistance relevant to</li> </ul>	<ul style="list-style-type: none"> <li>-Average increase in per capita income of 83%</li> <li>-Personal contribution to family income increase of 65%</li> <li>-51% increase in family access to latrines</li> <li>-Families reported eating 30% more per day (from 2 meals per day)</li> <li>-Of the initial surveyed population (2372 individuals) the average daily income was 28 cents</li> <li>-Most of the initially surveyed population were not well educated and did not own enough land for an</li> </ul>	<ul style="list-style-type: none"> <li>-Strong definition of target population ultra-poverty level</li> <li>-Results suggest that the intervention had a highly positive impact on the participants</li> <li>-The publication was easy to follow and understand</li> <li>-The intervention incorporates a community based research approach</li> <li>-The individualized plans assured that the participants had a say in what they wanted their goals to be</li> <li>-The intervention targeted a specific population that was not being reached by other</li> </ul>	<ul style="list-style-type: none"> <li>-Does not provide enough detail regarding data collection and the process of determining which variables/ characteristics to look at such as access to latrines</li> <li>-Because the intervention plan was so individualized for each participant it cannot be replicated and they don't include samples of plans for reference</li> <li>-Requires intensive resources and knowledge of the community and the individual to be effective</li> <li>-Results could have been affected by other interventions and initiatives active at the same time by other NGO's etc.</li> </ul>

<p>each situation was provided to the participants and their families (ex: money for education, money to build a latrine, or support to undergo vocational training)</p> <p>-The intervention also involved connecting individuals with their communities to develop their plans</p> <p>-The intervention worked to connect individuals with any government benefits they were eligible for and previously did not access</p> <p>-The intervention was designed to help people out of ultra-poverty so that they could then participate in other interventions that help individuals in a slightly better economic position such as microfinance services</p>	<p>agricultural livelihood</p> <p>-Land ownership increased slightly (20 individuals)</p>	<p>interventions and aimed to raise their standing so that they could then benefit from other interventions (it incorporated the already present aid environment)</p> <p>-The intervention took on a holistic perspective of the individual where their physical, social, and financial statuses were all taken into account</p> <p>-The intervention incorporated multiple levels into the planning, starting with the individual and moving up to also include their community and the government</p>	<p>-Change occurred incrementally which means it can be hard to convince future donors to invest in such a project</p> <p>-Need to link back to microfinance and why it doesn't work for people in ultra poverty because they talk about it earlier in the paper</p>
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### The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People

#### Affected by Leprosy in Indonesia

Lusli, M., Peters, R., van Brakel, W., Zweekhorst, M., Iancu, S., Bunders, J., ... Regeer, B.

(2016). The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia. *PLoS Neglected Tropical Diseases*, 10(12), e0005088. <https://doi.org/10.1371/journal.pntd.0005088>

Research Questions/ Objectives/ Study Aims	Setting	Sample	Data Collection Methods and Primary Outcomes
<p>-Part of existing Stigma Assessment and Reduction Impact (SARI) project</p> <p>-To assess the impact of a CBT counselling intervention on anticipated, internalized, or experienced stigma</p>	<p>-Cirebon District, Indonesia</p>	<p>-People with leprosy and their families</p> <p>-Cluster randomized sampling</p>	<p>-Three main collection points (no exact time given) included baseline data, interviews throughout the intervention, and a final survey</p> <p>-Used various types of data collection and measurements</p>

<p>through individual and social levels</p> <p>-To use various types of counselling including individual, group, and family counseling and to see how effective each type is</p> <p>-Hypothesis is that the counselling will be effective in combatting stigma and thus improving standard of life</p> <p>-Training community members to be peer counsellors to improve stigmas for those peers and the people they are counselling</p>			<p>-To measure stigma: Participation Scale Short (PSS), Sari Stigma Scale (SSS), and WHO-Quality of Life (WHO-QLL BREF)</p> <p>-Note: the WHO-QLL BREF was not collected for all participants (the researcher would forgo survey if participant seemed weary)</p> <p>-Participant notes to analyze benefits of these sessions -</p> <p>Counsellor notes to analyze types of stigma experienced by participants</p> <p>-Interviews focused on “leprosy history, feelings, family and friends, community, economic condition, and future”</p> <ul style="list-style-type: none"> <li>· Tried to collect corresponding data from the same participants pre and post intervention, but only were able to do so with some of the participants</li> <li>· Use of both trained leprosy workers, project’s research assistants (some of whom affected by leprosy), and peers who were trained extensively</li> </ul> <p>-Used Epi for Windows database and Stata 12.1 programs</p>
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<b>Describe the Intervention and Comparison Conditions</b>	<b>Key Study Findings</b>	<b>Study Strengths</b>	<b>Study Limitations</b>
<p>-Control group did not receive intervention, but was in the same area that the SARI program was taking place</p> <p>-Interdisciplinary approach using CBT methods</p> <p>-Took place over 2 ½ years</p>	<p>-46% of participants dealt mostly with internalized stigma</p> <p>-27% dealt mostly with anticipated stigma</p> <p>-19% dealt mostly with enacted stigma</p>	<p>-Study did a good job of training personnel so that the intervention would be able to continue and have further effects</p> <p>-Two year time period</p>	<p>-The control group had much lower baseline levels of stigma, which makes it harder to see a change</p> <p>-Control group also had reduced stigma levels, although they could be</p>

<p>-Non-randomly selected people to be peer counsellors, including some of the research assistants</p> <p>-56 hours of training</p> <p>-Five sessions of counselling (first three lasting between 30-45 minutes and last two lasting between 45-60 minutes)</p> <p>-Individual, family, and group counselling offered to address ignorance surrounding the disease and the rights of people with it, to show support in a group, and to build trust</p> <p>-In actuality, number of sessions received differed by client's individual needs</p>	<p>-8% said they experienced no stigma</p> <p>-Both the control group and the intervention groups saw decreases in stigma levels on the SSS and PSS measures indicators, but the intervention group had a much bigger decrease</p> <p>- The mean difference SSS and PSS scores between the intervention and control groups were not statistically significant</p> <p>-The control group lost quality of life (down 2.00 points) according to the WHOQOL-BREF scores, but the counselling group improved by 6.54 points</p> <p>-Sex had a large effect on perceptions</p> <p>-Women had higher levels of stigma before the intervention, but also had a bigger impact from the intervention than men</p>	<p>shows effectiveness of long term intervention</p> <p>-Use of CBT and researchers with various disabilities makes the community have more trust of the intervention and researchers</p> <p>-Use of these three counselling interventions was very effective</p> <p>-Box 1 does a very effective job in showing what the necessary attributes of the counsellors were and what they would teach during the counselling sessions</p> <p>-All of the tables present new data and information that is not repetitive</p> <p>-By using three different types of stigma tests there is better convergent validity</p> <p>-The intervention is very individualized which makes it more effective for combatting perception based things like stigma</p> <p>-Intervention gave economic incentives that allowed community perspectives to improve</p> <p>-Figure 1 shows very well how the final 67 counselling clients were chosen from the original 523 people in the baseline</p>	<p>explained by the passage of time or the SARI program</p> <p>-The study was unclear as to how it chose the participants who would become peer counsellors</p> <p>-The report combined data from the pilot and from the actual intervention despite changes in the study design</p> <p>-Hard to implement three different kinds of counselling</p> <p>-Hard to train personnel and hard to assess whether peers will be considered knowledgeable enough by other participants to have an impact – in this study some participants liked it and some did not</p> <p>-The data could be impacted in the interviews by participants giving the answers that they know researchers want to hear</p> <p>-How effective is it to have research assistants do both conducting of research as well as administration of the intervention as counsellors?</p> <p>-Had only approximately a third of interviews in the final survey as they did in the baseline, which makes the follow-up data hard to analyze</p> <p>-In the ethical considerations, participants were given written consent forms, but it is unclear whether any special consideration was given to vulnerable populations that were included in the study or if consideration was given to people who could not read</p> <p>-Economic incentives are hard to implement everywhere and it is unclear how the “SED-related activities” played a role in reducing stigma in the data results</p>
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As is the case with many neglected tropical diseases, leprosy research does not receive an appropriate amount of resources. This is exemplified by the fact that transmission of the disease is still unknown. Although the interventions in this paper focus on social aspects of leprosy, many medical evidence-based interventions exist to prevent morbidity. For example, multidrug therapy has proven to be an effective method for treating leprosy (van Veen & Richardus, 2008). However, more evidence is needed to examine how social determinants affect leprosy. Poverty proves to be one of the largest challenges to preventing the transmission of leprosy (Nery et al., 2014). Additionally, poverty acts as a barrier between people with leprosy and existing treatments and interventions (Bowers, Singh, & Kuipers, 2014).

One major gap in the evidence is a lack of generalizable knowledge for social interventions due to the focus of studies on specific regions. There is also a gap in research regarding leprosy and stigma. Stigma remains an issue that is debilitating to families and individuals and reduces productivity. The Indonesian stigma intervention shows the lack of a significant statistical success in combating this. More evidence is needed to show why some people are affected by internalized, expected, and experienced stigma (Lusli et al., 2016). While there are few effective interventions for reducing stigma, interventions that aim to improve economic standing significantly reduce leprosy transmission and morbidity due to increases in ability to access care. More evidence is needed to understand the effectiveness of cash transfer programs and their effect on the epidemiological factors related to leprosy (Nery et al., 2014). In order to achieve the World Health Organization's goal of eradicating leprosy more resources need to be dedicated to evaluating and implementing effective leprosy interventions (WHO, 2016).

### **Evidence Based Practice Intervention**

#### **Bolsa Familia Program and Family Health Plan to Address Poverty and Leprosy**

The Bolsa Familia Program is a conditional cash transfer program that was instituted by the Brazilian government in coordination with the Family Health Plan (FHP), which is an expansion of Brazil's national healthcare program, the Sistema Unico de Saude. Families must access healthcare through the FHP as well as meet education requirements for children before they can receive the Bolsa Familia cash transfer. By combining the Bolsa Familia Program and the FHP, this intervention addresses poverty, the root cause of leprosy. We propose to adapt this intervention to add financial counseling resources for individuals with leprosy and their families living in ultra-poverty. The concept of financial counseling and its proven effectiveness come from the "Responding to the challenge of leprosy-related disability and ultra-poverty" intervention in Bangladesh. In the Bangladesh study ultra-poverty is defined as the inability of a person to consume 2100 kcal per day (Bowers, Singh, Kuipers, 2014). There is a similar community of people in Brazil who experience severe financial challenges and can also be defined as living in ultra poverty. The financial counseling services will be provided as an option for people and families affected by leprosy in the Family Health Program clinics. In addition, financial counseling videos will be displayed in the waiting rooms for everyone to view. The adapted intervention will also train and employ community members with leprosy to provide the financial counseling to other people and families affected by leprosy as a way to include the community and reduce stigma around the disease. By incorporating primary care services, cash transfers, long term financial planning, and jobs for individuals with leprosy, this intervention addresses multiple

issues associated with leprosy and helps pull families out of poverty, therefore eliminating the primary risk factor for leprosy.

Poverty is a primary risk factor for contracting leprosy around the world. Consequently, in Brazil, the poorest regions are most heavily affected by leprosy. An intervention that addresses both poverty and the prevalence of leprosy is necessary in order to eradicate leprosy in Brazil. The Bolsa Familia Program is a conditional cash transfer program that was instituted by the Brazilian government in 2003. It targets “poor families” which are defined as those with a monthly family per capita income of less than 120 Brazilian reais or 57 American dollars (Lindert, Linder, Hobbs, de la Briere, 2007). In order to be eligible for the Bolsa Familia Program, families must access basic health care, pre and postnatal care, vaccination, and nutritional growth monitoring of children ages 0 to 7. In addition, there are education requirements that children have 85% school attendance in order for parents to receive the cash transfer (Lindert et al., 2007). By requiring families to access healthcare and education before receiving the cash transfer, the Bolsa Familia Program addresses poverty, the root cause of leprosy.

Since families that are part of the Bolsa Familia Program are required to access healthcare in order to receive the cash transfer, it is necessary that settings exist for poor Brazilians to access care for free. The FHP is an expansion of Brazil’s national healthcare program, the Sistema Unico de Saude (SUS), and offers free primary health care in Brazil’s most deprived regions (Nery et al., 2014). Given that long wait times and below average care have previously plagued the Brazilian national healthcare system, the FHP is decentralized and is organized at the municipality level using multi professional teams that include dentists, doctors, nurses, and community health workers which leads to sustainable

community based care (Nery et al., 2014). The existing infrastructure has the capacity to accommodate the new additions to this intervention because it is nationally funded and has clinics throughout Brazil with one health care worker assigned to every 150 families (Macinko and Harris, 2015). By combining the Bolsa Familia Program and the FHP, leprosy and its primary risk factor, poverty, can be addressed simultaneously. The FHP provides a primary care visit where people can be screened for leprosy, therefore allowing more people being treated before they can transmit the disease to others.

Both the Bolsa Familia program and the FHP are resource intensive interventions, however, because there is government support for the programs, they are sustainable interventions that address the burden of leprosy. Both are also programs that are already instituted in Brazil, so barriers around societal acceptance and implementation are reduced. Poor Brazilians are already used to accessing healthcare services through the Sistema Unico de Saude national healthcare system and aid from the Bolsa Familia Program since both are established programs. The Bolsa Familia Program has existed since 2003 and the FHP has existed since 1994 (Nery et al., 2014). As shown by Nery et al. (2014), combining the FHP with the Bolsa Familia Program proves to be an effective intervention for controlling leprosy and reducing poverty.

### **Improving the Social and Financial Standing of People With Leprosy Living in Poverty**

The Bolsa Familia Program and FHP intervention alone is not enough to eradicate leprosy in northeastern Brazil because they do not specifically target leprosy, rather the general health of Brazilian populations. In addition, the Bolsa Familia Program provides cash transfers which improve the financial well being of beneficiaries at the time of the

transfer, but does nothing to address the long term financial well being of Brazilians living in poverty, especially those who may be disabled due to leprosy. Without treatment, leprosy can cause disabilities that prevent people from working, thus destining families with disabled primary earners to a life of poverty. It is also expensive for the Brazilian government to continuously provide cash transfers to the poorest Brazilian families through the Bolsa Familia Program. Offering optional long term financial planning services in which counselors who have leprosy themselves work with impoverished individuals with leprosy and their families to help the families make better use of the money they receive through the Bolsa Familia program is an important component in order to address the long term financial well being of families affected by leprosy. The intervention would work to bring the families who opted for the services out of poverty and address the primary risk factor for contracting leprosy, poverty, while making the Bolsa Familia program more sustainable long term.

An intervention implemented in Northwest Bangladesh that had counselors create individualized goals and plans with families who have members disabled by leprosy was effective at improving both the social and financial standing of the participating families (Bowers et al., 2014). This intervention was successful in that it lead to an increase in per capita income of 83% among those who participated. However, this intervention may be hard to replicate exactly in Brazil because in Bangladesh every plan was uniquely designed to fit the assets and goals of each family, therefore no set protocol exists for how to help families in general (Bowers et al., 2014).

This intervention could not be applied to the same degree in northeastern Brazil as it was in Bangladesh because of its resource intensive nature for each family. However, a

more resource efficient addition of financial planning services to the Bolsa Familia program would still likely improve the long term financial status of families living in poverty who have a member with a disability due to leprosy. Although the threshold for poverty in Bangladesh is lower than the threshold in Brazil, living on 15 to 30 American dollars per month compared to 57 dollars per month respectively (Bowers et al., 2014 and Lindert et al., 2007), both groups are considered to be among the poorest in their respective countries and both groups receive financial assistance from the government. In addition, the whole family is involved in the financial planning instead of just the person disabled due to leprosy. This approach would be culturally acceptable among Brazilians given the importance of the family unit and because the assistance unit of the BFP is the family, not the individual (Lindert et al., 2007).

A change that would need to be made from the original intervention in Bangladesh to the adapted intervention in northeastern Brazil would be that the intervention in Bangladesh was implemented by going from door to door. This approach to implementing the intervention is resource intensive and inefficient. Given that many families affected by leprosy in northern Brazil are transitory due to their search for work, it is inefficient to move door to door. A participating family may move during the implementation of the intervention, thus exposing the intervention to a high rate of dropout participants due to lack of follow up. Instead, it would be effective to have the financial planning and goal setting services occur in the clinics where people access primary care visits through the FHP. These clinics are part of a national program and therefore exist in every region, so the intervention would be accessible to families and individuals with leprosy even if they move. The financial planning counseling services could be delivered while people wait for their

appointment at the clinics, thus turning the long wait time at clinics into a productive period during which people can attain useful financial planning education. Additionally, screening financial planning videos in the waiting rooms of the clinics would provide this critical information to all families living in poverty in Brazil, not just those with members who have leprosy. Ideally, all families living in poverty in Brazil would be able to receive the individualized financial planning counseling, however, the intervention only focuses on people with leprosy for the time being because they are disproportionately affected by poverty.

### **Reducing Stigma Surrounding Leprosy**

Another proposed addition to the Bolsa Familia Program and FHP intervention is a stigma fighting component. Physical malformations identify those who have leprosy which can lead to stigmatization of those affected by leprosy. People with leprosy can be ostracized from communities and can also struggle to find jobs due to disability or physical malformations. An intervention in the Cirebon District of Indonesia attempted to reduce stigma through counseling. Although the results of the stigma counseling services were statistically insignificant in the Indonesian intervention, one aspect of the intervention did prove to be helpful: hiring individuals with leprosy to provide counseling (Lusli et al., 2016). This portion of the intervention can be applied to the northeastern region of Brazil by training and employing individuals with leprosy to provide the financial counseling services at the clinics. This adaptation would help our proposed intervention involve the communities and local individuals with leprosy. The employment of people with leprosy would add a second target population to the intervention so that it addresses both people seeking care at the clinics and people seeking employment. There is no statistical evidence

that this method will reduce stigma, however, employment of people with leprosy is an important part of addressing poverty, since people with leprosy often struggle to find employment. More research is needed surrounding effective methods for reducing stigma around people with leprosy before a thorough stigma fighting component involving changing the perceptions of people without leprosy to understand individuals with leprosy can be fully included in this intervention.

The FHP and Bolsa Familia Program combined with the long term financial planning education services component of the intervention from Bangladesh and the concept of employing of individuals with leprosy taken from the Indonesian intervention can address the immediate health needs of people with leprosy, prevent the transmission of the disease through early screening, and improve the financial status of those living in poverty. By helping get people out of poverty, the primary risk factor for the disease is addressed. Leprosy can be eradicated in northeastern Brazil, however, steps need to be taken to improve the financial well being of people and bring them out of poverty.

### **Implementation of Evidence Based Practice**

Our proposed intervention is unique because it does not need to implement new infrastructure, but rather builds off of the existing framework of FHP in Brazil. The FHP is part of the Brazilian unified national health care system (Nery et al., 2014), which makes it affordable to people of all socioeconomic statuses and thus will allow even people living in ultra-poverty to access care. The requirements for the cash transfer will maintain the same and continue to include education and primary health visit standards. The combination of the Bolsa Familia program and the FHP provides resources that allow families and individuals

affected by leprosy to have continued access to care and to cash transfers despite their highly stigmatizing, and in late stages, highly deforming disease.

For the adapted intervention to be the most successful in reaching people of low income in Brazil and for targeting the migrant population that is common in the northern regions, it is necessary to add on to the existing infrastructure of the FHP by making the financial services clinic centered. As previously mentioned, the financial counseling intervention in Bangladesh was originally implemented on a door-to-door basis, but because this has the potential to exclude the migratory population it is extremely important to implement this intervention at clinics. These clinics should all have a standard protocol across Northeastern Brazil so that people can still have access to the clinical care and financial counseling resources no matter where they are.

This standard protocol must be trifold, including regular screening implemented into primary care visits by healthcare workers educated about leprosy, optional financial resource counseling, and video programming for financial resource education in waiting rooms. Screening should be done by educated healthcare workers who have the skills to identify the early stages of the disease despite its confusing trajectory and outward signs so that it does not progress into more aggressive forms of the disease. These providers must also be able to offer MDT to combat the spread and progression of the disease. They must also counsel the patients on how to take the drugs so that they understand the importance of MDT in halting the transmission of this disease and preventing its progression.

Community members with leprosy can be trained to offer optional financial counseling for leprosy patients in our intervention. Employing people with leprosy will help to combat stigma. Including these people in the implementation demonstrates that contact

with people who have leprosy is safe once they receive treatment. This portion of the intervention also offers these marginalized individuals an employment opportunity. The justification for including this part of the Indonesian intervention comes from the anecdotal evidence in the intervention report. The researchers from the Indonesian intervention found that people with leprosy felt much more confident in their ability to hold a job and be an active part of their communities when they communicated with and learned from employed people with leprosy. The anecdotes indicate a lesser amount of self-perceived and expected stigma, even though the statistical analysis of the study did not find a significant impact. Because this is a matter of qualitative data, the anecdotal evidence and survey responses arguably outweigh the findings from the statistical analysis in the Indonesian intervention.

The training program for the financial counselors from the Bangladeshi intervention was not specified in the report. In order to have the same results, we would need to contact the researchers to get the specific details on their suggested six-week training implementation. Although it is resource intensive to train new staff, it is necessary to involve community members who understand the needs of both the local community and the leprosy community. This also would work well in conjunction with the FHP which strives to improve coordinated care (Nery et al., 2014).

While the Bolsa Familia is an integral part of this intervention because it helps to reduce the prevalence of the primary risk factor for leprosy, poverty, it is necessary to supplement the cash transfers with financial resource counseling. The effectiveness shown in the Bangladeshi intervention shows that financial resource counselling has a major improvement on wealth and an average of an 83% increase in per capita income (Bowers et al., 2014). In the original Bangladeshi intervention, researchers met with families then spent

up to two days formulating a 3-5 year plan incorporating the individual goals of each participant. For our proposed intervention, the financial counselors would need to have a preliminary meeting to discuss financial goals with the participants as was done in the Bangladeshi intervention. However, instead of then having the counselor spend up to two days focusing solely on one participant, the counselors in our adapted intervention would create plans for multiple participants over longer stretches of time. Using staff who have been trained and working with the community and family members to create a 3-5 year plan that is individualized to a specific family's needs improves their long-term wealth and financial standing. The specifics of the counseling plan developed in the intervention are not described by the researchers in their report, partially due to the individualized nature of the intervention; however, in our implementation protocol we would contact the researchers to access the specifics of the counseling curriculum. This would allow our intervention to have the same positive results that they had. The population in Brazil that contracts leprosy is similar to the targeted population in the Bangladesh intervention in that participants may also have low literacy levels. Therefore, the training and counselling will be administered in person and based off of visuals rather than on written text. Furthermore, the counselling needs to include practical assistance including how to use money for building latrines or attaining higher levels of education. Training individuals with leprosy to conduct this counselling will further the intervention's connection to the community and help the participating families to improve their plans and access government benefits. In order to have the largest benefit, it is also necessary to focus on inclusion of women in the financial resource counselling sessions because research has shown that women are more financially

responsible and therefore the Bolsa Familia Plan cash transfer goes directly to the women in the household 93% of the time (Lindert et al., 2007).

The last tier of this intervention will involve financial counseling video services in waiting rooms. Waiting rooms in the Family Health Program often involve long wait times, so by adding educational videos to the waiting rooms the entire community can benefit from the financial resource counselling. Additionally, about 70% of Brazil's population receives care from the FHP and the Sistema Unico de Saude in Brazil (WHO, 2008), so accessing this resource will not stigmatize people by distinguishing them as people who need financial help. It will allow the greatest amount of people to access the resources in the least resource intensive way. The visuals in the video will also help to avoid marginalizing illiterate patients and make sure that everyone can benefit from the resource. Videos in waiting rooms will bring the intervention to more people who would have otherwise been unaware of these services. The downside to this implementation format is that it will not reach people who do not access primary care. This downside is offset by the addition of the intervention to clinics on a broad scale with a uniform protocol where it can reach the most amount of people. Because this is an extension of the Bolsa Familia Program, families should already be accessing primary care to qualify for the cash transfers (Nery et al., 2014), which will assure that the most people access these resources.

The government is the primary source of funding for the FHP and Bolsa Familia programs, which means that securing financial resources is not a big barrier because it is only an alteration and extension of the existing interventions. However, because this intervention relies heavily on government support, continued government funding is vital to its continued effectiveness. Leprosy can often be confused with other skin conditions

because it can manifest itself in such a diverse range of ways (Fischer, 2017). While this is clinical and is thus resource intensive and costly, another key aspect of this is to involve community members, particularly those with leprosy. As was shown in the intervention in Indonesia, it is helpful for leprosy patients to see other people with the disease as an example that they too can be high achievers by seeking employment and making themselves visible in their communities.

### **Evaluation of Evidence Based Practice Intervention**

The Bolsa Familia Program is currently evaluated by looking at the new case detection rate of leprosy, the per capita income, and the poverty rate in Brazil. The program uses these statistics to measure the success of the intervention at the national, state, and municipality levels (Nery et al., 2014). The proposed adapted intervention from this paper would only be implemented in northeastern Brazil and therefore the evaluation will take place predominantly on the state and municipality levels with individual evaluation through survey and interviews; however, the unadapted Bolsa Familia program and FHP will continue to exist in other regions of Brazil. This adapted intervention will not include national statistics because northern and southern Brazil have markedly different health outcomes and therefore the regions cannot adequately be compared to determine the success of this intervention (Nazario et al., 2017). The new case detection rate is expected to rise initially due to the increase in screening and promotion for individuals with leprosy to seek health care services. However, over time the incidence of leprosy should decrease as a result of decreased poverty rates, improved living conditions, and better leprosy education for individuals with leprosy.

The impact of the addition of financial counseling to health care clinics can be evaluated by collecting per capita income data as well as data regarding the individual contribution that a person with leprosy adds to their family income (Bowers, et al., 2014). The addition of stigma counseling can be evaluated by looking at the graduation rates of a community, and specifically of individuals with leprosy, because education is directly correlated to improved health and less poverty (Lusli et al., 2014). Additionally, tracking trends in Disability Adjusted Life Years for individuals with leprosy can offer insight into how well financial counseling improves a participant's abilities and quality of life.

This data can be collected as part of general regional statistics collected through the Bolsa Familia program. Furthermore, at the end of financial counseling meetings the trained counselors can conduct a verbal interview or survey regarding the participant's experience with the intervention and how effective they believe the counseling and education components were. Collecting data on the participants' experiences is important due to the sensitivity of leprosy as a health issue. If participants felt uncomfortable at any point of the intervention it is critical for the people implementing the intervention to address the discomfort so as to avoid promoting yet another environment in which individuals with leprosy experience stigma. Qualitative questions on the survey should also address how the participants felt about having a financial counselor who has leprosy as well to assess the effect of employing people with leprosy on combating stigma that study participants perceive. The data should be collected over the course of several visits to the clinic so as to evaluate the longitudinal effectiveness of the intervention. Longitudinal data collection would allow us to adapt the intervention based on community feedback and the constantly evolving needs of specific communities throughout the region. There will not be a control

group in this intervention because it would be unethical to withhold the counseling services from people with leprosy in the communities. The longitudinal data collection methodology would instead allow us to evaluate the effectiveness of the intervention using a pre-intervention baseline as compared to post-intervention data.

Given that poverty is a primary risk factor for leprosy, the Bolsa Familia Program combined with the FHP has proven to be an effective method for controlling leprosy and reducing poverty (Nery et al., 2014). The additions suggested in this paper should help these general national programs specifically target and aid individuals with leprosy. Since the Bolsa Familia Program and the FHP are already established national programs, it is assumed that additional funding for these leprosy-targeted services could be provided. However, a limitation of this intervention is that the exact cost and related effectiveness of adding these financial counseling services is unknown. Other studies have shown that financial counseling is beneficial to individuals with leprosy, however adding the services onto an already established program base has the potential to distract from the services that are successful when they stand alone (Bowers et al., 2014 and Lusli et al., 2014). Furthermore, this intervention relies heavily on the stability of the Brazilian government in that it is the main funder for the infrastructure and resources.

While offering additional financial counseling in a primary care setting would be efficient for the participants it would also be resource intensive in that intervention staff need to be properly trained and educated specifically on the multi-faceted nature of leprosy. This intervention focuses on reducing morbidity and improving the quality of life for individuals with leprosy in that it takes on a holistic perspective to health by incorporating their financial, mental, and social well-being. While the cause of leprosy transmission is still

unknown, it is established that areas of low income and low quality of life have increased transmission. Therefore, this intervention is also expected to decrease transmission because it improves the quality of life of individuals in the area.

### **Conclusion**

Leprosy and its root cause, poverty, need to be addressed in northeastern Brazil by combining primary health care with financial assistance and counseling. By implementing a multi-pronged plan that targets people living in poverty, it is possible to decrease the prevalence and incidence of leprosy in northeastern Brazil. While Brazil has achieved the WHO goal of eliminating leprosy nationally, extreme disparities exist between the poorer northern region and the richer southern region. Efforts need to be focused at the regional level since national elimination has already been achieved (WHO, 2016). Because the international community is so close to reaching the goal of eradicating leprosy, it is vital that resources are allocated strategically in the remaining endemic areas, which are concentrated in the poorest regions of the world, such as northeastern Brazil.

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