

THE LEGACY OF BRAZIL'S LEPER COLONIES

O legado das colônias de lepra no Brasil

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ABSTRACT

The meaning of Hansen's disease in Brazil has hit an important crossroads. Twenty years after the introduction of multi-drug therapy, the government of Brazil has agreed to pay an indemnity to patients isolated in the leper colonies. Two conflicting images of the disease therefore continue to clash in the minds of Brazilians: one of a disease that is easily cured, and one of an affliction that causes unimaginable suffering. In order for the government's program to be successful, it must first reconcile these images by understanding the policy decisions of the past. Contrary to popular belief, the leper colonies were not simply a reflection of international scientific thought, nor an outgrowth of a longstanding stigma, but the work of a powerful group of scientists who supported isolation for political, cultural, and personal reasons. Uniting with the government, these scientists were able to create a program of isolation that was out-of-step with contemporary international recommendations, masking the policy's flaws in a reinvention of the disease's past. Only by deconstructing their work can we deconstruct the myths surrounding Hansen's disease, and thus chart a new course for the disease's treatment.

KEY WORDS

Hansen's disease, patient isolation, stereotyping

RESUMO

O significado de hanseníase no Brasil encontra-se em um importante dilema. Vinte anos depois da introdução da poliquimioterapia, o governo do Brasil aprovou uma indenização para pessoas que foram isoladas em colônias pelo governo. O resultado é que, no Brasil, existem duas imagens divergentes: uma de uma doença fácil de curar, e outra de uma aflição que causa grande sofrimento. Para o programa de eliminação ter sucesso, o governo terá que primeiro reconciliar essas imagens e entender as políticas do passado. Esse artigo refutará o consenso popular, que as colônias foram criadas de acordo com o pensamento científico daquela época, ou por causa de um estigma eterno e constante. Ao contrário, a construção das colônias foi um projeto de um grupo poderoso de cientistas por razões políticas, culturais e pessoais. Com o apoio do governo, esses cientistas criaram um programa de isolamento em conflito com recomendações internacionais, escondendo as falhas da política numa reinvenção

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do passado da doença. Somente se decomposermos este trabalho poderemos desconstruir os mitos da hanseníase, e achar um novo caminho para o tratamento da doença.

PALAVRAS-CHAVE

Hanseníase, isolamento de paciente, estigmatização

1. INTRODUCTION

Twenty years after the introduction of multi-drug therapy, the government of Brazil has agreed to pay an indemnity to patients isolated in the leper colonies (Agência Estado, 2007). Two conflicting images of the disease therefore continue to clash in the minds of Brazilians: one of a disease that is easily cured, and one of an affliction that causes unimaginable suffering. In order for the government's program to be successful, it must first reconcile these images by understanding the policy decisions of the past.

Contrary to popular belief, the leper colonies were not simply a reflection of international scientific thought, nor an outgrowth of a longstanding stigma, but the work of a powerful group of scientists who supported isolation for political, cultural, and scientific reasons. Uniting with the Vargas government, these scientists were able to create a program of isolation that was out-of-step with contemporary international recommendations, masking the policy's flaws in a reinvention of the disease's past. Only by deconstructing their work can we deconstruct the myths surrounding Hansen's disease, and thus chart a new course for the disease's treatment.

Of the indemnity granted ex-patients, President Lula reportedly said, "*It is an atonement of justice, one of many that we should make*" (Agência Estado, 2007). But what was the root of this injustice? Was the policy of isolation simply a mistake? Was it driven by prejudice, religious beliefs, or scientific evidence? Did the scientists who pushed for this isolation have a choice? Or more to the point, in spite of the undeniable harm that leprosy isolation caused, did Brazil benefit from the segregation of these people from society?

Many believe that the leper colonies were the inevitable outgrowth of leprosy's stigma, misconstruing the political realities of this massive public health program, and exaggerating the natural repugnance to the disease. These explanations have led to confusion in the colonies, as well as among the general public. In this article, I will attempt to demonstrate that a group of scientists misrepresented the threat of leprosy in order to legitimize their claims about the disease and a controversial new disease model: germ theory. These same scientists were also concerned about the image of Brazil abroad, and the threat leprosy supposedly presented to European immigration. Unsuccessful in their quest to isolate lepers during the colonial and Republican periods, when isolation was recommended by

leprologists around the world, they eventually won the support of President Getúlio Vargas, framing leprosy as an issue of national progress.

Compulsory isolation allowed Brazilian scientists to definitively prove their model of the disease's transmission. But ironically, isolation has facilitated the continued spread of the disease by increasing the stigma and confusion surrounding it. Moreover, it has had a devastating and destabilizing effect on the lives of those who were isolated. By understanding the origin of the two disparate experiences of leprosy and Hansen's disease, Brazil can attack both problems at once, and rescue the dignity of the disease's victims.

2. METHODOLOGY

This article is based on two years of ethnographic and historical research conducted in Brazil from 2005 to 2007. Ethnographic research consisted of nine months of participant-observation in four leper colonies across the country, along with thirty on-site interviews with patients residing in those colonies. Interviews were recorded and transcribed, and they focused primarily on patients' life histories. I also observed dozens of clinical encounters in outpatient centers and interviewed clinicians and support staff working in the colonies. Historical research focused on government documents, journal articles, newspaper reports, hospital records, and published histories. Historical research was conducted as part of the Archival Project, a collaboration between the "Movimento para a Reintegração de Pessoas Atingidas pela Hanseníase" and Oxford University, which is working to preserve the history of the colonies for future generations. Recent scholarship has revealed that political bias permeates many of the primary documents written by scientists and policy-makers; and this article presents a rereading of those primary documents in an effort precisely to bring those political aims and biases into relief.

"SE CUIDA": LEPROSY TO HANSEN'S DISEASE

In a leper colony outside of Rio de Janeiro, Curupaiti, where I worked for seven months during 2007, residents occasionally counsel those who are recently diagnosed with Hansen's disease. "You have Hansen's disease," I heard one resident say to a young man, who had come to have his bandages changed. "But take care of yourself, or you'll get leprosy." The interaction became an oft-repeated joke among employees of the hospital, who considered the explanation to be more evidence of the residents' deep-seated ignorance about their own disease. I did too. But in the time that I have had since to reflect on this peculiar community, I believe that this resident demonstrated more astuteness about his disease than I had. He had lived his life with leprosy. He had been officially sanctioned a leper by the Brazilian government. He had been forced to give up his family outside

the colony, and — because “healthy” children were removed from their “sick” parents — all hopes of creating one within. By contrast, the younger man had Hansen’s disease, which could be treated with antibiotics and controlled through diligent hygiene. Though he may have suffered discrimination, he could come and go to the colony as he pleased. As long as he did not develop the visible disabilities associated with Hansen’s disease, he could conceal it from the world.

The most well-known narrative of leprosy history is that of one long, unbroken tradition of repulsion and segregation, until the discovery of a cure and the phasing out of the leper colonies. It is often assumed that Brazil’s scientific community had no choice but to isolate leprosy patients, that no other method of containment was known or available. Several medical historians, notably Diana Obregón Torres, have poked holes in this theory, resurrecting scientific debates about the efficacy of leprosy isolation (Torres, 2002). Similar dialogue about the situation in Brazil has started along the periphery, but as of yet has not been incorporated into mainstream historical or policy discourse.

Modern-day leper colonies (beginning in the late 19th century in many countries, and the 20th century in Brazil) (Poorman, 2006) represent a unique chapter in the disease’s history. In Brazil, the Vargas dictatorship, political repression, and a policy of “cultivating” the Brazilian population through European immigration, all fed into a propaganda machine surrounding leprosy isolation, which, among other tactics, exploited the idea of traditional repulsion to the disease. It is my intention with this paper to show that the necessity and efficacy of leprosy isolation was hotly debated in Brazil, that the efficacy of isolation was never clear, and that the decision to isolate leprosy patients was made as much for political reasons as scientific ones. Moreover, and perhaps most pertinent to public health officials, the leper colonies facilitated the spread of Hansen’s disease in Brazil, and continue to thwart its eradication. A historical perspective, currently absent from eradication programs, is essential if we are to learn from the mistakes of isolation, successfully control the disease’s spread, and appreciate the sacrifices that Hansen’s patients and their families have made.

FRAMING DISEASE

In order to understand the evolution of policy decisions, it is important to remember that the history of a disease cannot be continuous, as the meaning of a disease changes through time. This concept is best explained by Charles Rosenberg, who writes:

“...disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine’s intellectual and institutional history, an occasion of and potential legitimation for public policy, an aspect of social role and individual — intrapsychic —

identity, a sanction for cultural values, and a structuring element in doctor and patient interactions." (Rosenberg, 1992)

Leprosy has served all of these roles, as a battle ground for public officials, an identity for individuals, and a legitimization of oppression. Rosenberg's main thesis, that in "some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it" (Rosenberg, 1992) is particularly relevant to the history of leprosy, where the name has led to the conflation of different diseases and concepts.

Currently, leprosy is more or less equated with Hansen's disease. But the former is as much a social condition as a bacterial disease, while the latter is a highly medicalized affliction in which the bacteria is considered far more important than the experience of the disease.- To state it more simply, to call oneself a "Hansen's patient" (*hanseniano*) is to talk about the presence of an invading bacteria, while to call oneself a "leper" (*leproso*) is to subjugate the biological definition to the social experience of the disease. Historiography and the process of translation and interpretation have caused several historical diseases to be known as "leprosy." Therefore, it is not that leprosy was consistently believed to be repulsive, but that repulsive diseases were consistently given the name of "leprosy." Renaming leprosy "Hansen's disease" is as much a reflection of the shifting view of disease, in which the causal agent is paramount, as an attempt to conquer the disease's stigma. The conscientious motivations behind the name change have largely failed because there is little clarity on this concept, both among academics and the general public.

BIBLICAL EXPLANATIONS

In Brazil, "leprosy" is commonly used to refer to any number of dermatological conditions, including Hansen's disease, as well as a disease common among dogs. Each of these conditions bears its own stigma, complicated by leprosy's powerful religious connotations. In a country in which faith is the backdrop to all things, ordinary and extraordinary, prejudices are commonly blamed on religious groups, and the Bible is seen as the root of exclusion. This assumption has continued in spite of the fact that the Old Testament describes elaborate quarantine and cleansing rituals that have little to do with modern isolation; the New Testament shows Jesus' compassion to "lepers"; and none of the several diseases referred to in the Bible are Hansen's disease, as has been known since at least 1890 (Davies, 1890; Freilich, 1982).

This confusion was exploited by Brazilian scientists wishing to isolate leprosy patients, notably Belisário Penna, author of *O Saneamento do Brasil* and, briefly,

director of sanitation at the National Department of Public Health (*Departamento Nacional de Saúde Pública*) in the early years of the Vargas dictatorship. Three years before Vargas took office, Penna printed “Latent Leprosy and its Dangers” attempting to call the attention of the government to the problem of leprosy in the country. He begins:

“No other sanitary problem exceeds leprosy in importance, horrible contagious disease, chronic, repugnant... The most ancient of the known diseases, shamefully known in the book of Job — “the oldest daughter of death” — it has challenged until today the wisdom and the patience of researchers around the world, who have been unable to dominate it through treatment, nor remove the darkness that surrounds the biology of its causal agent...”
(Penna, 1927)

Here Penna offers a reference to the Book of Job as a backdrop for modern-day scientific uncertainties. Whether or not Penna chose to believe that Job was referring to modern-day leprosy in spite of the fact that the symptoms in the text more closely resemble scabies (Appelboom *et al.*, 2007), or whether he was simply using the passage as a propaganda tool is unknowable. The narrative effect, however, is to turn modern-day scientists into the new priests, the rightful heirs of the treatment of leprosy, in spite of their serious scientific doubts.

HISTORICAL ARGUMENTS

Scientists across the world championed isolation, relying on historical constructs although scientific evidentiary support of their theory was lacking. While 20th century historians long believed that these scientists were referring to widespread beliefs and superstitions that were the vestiges of the Middle Ages, several historians, led by Zachary Gussow, have shown that these scientists were in fact resurrecting long-forgotten images and crafting them to their own purposes (Gussow, 1989). This discovery has become very familiar in leprosy history. I would add only that the resistance to seeing disease as a function of its context and not just its biology has kept this idea from reaching widespread acceptance, especially outside the historiography of leprosy.

Historical arguments were used most famously in Brazil by Heraclides César de Souza Araújo, author of the monumental *The History of Leprosy in Brazil* (*A História da Lepra no Brasil*), and head of leprology research at the Oswaldo Cruz Institute from 1927 to 1956. In 1930, Souza Araújo wrote “The Imparity of the Problem of Leprosy in European countries or The History of Leprosy in Europe.” (Souza Araújo, 1930). The article begins with references to the mystical treatment of leprosy in the Middle Ages, including the acts of saints considered capable of

curing leprosy. It may appear to modern observers that Souza Araújo's inclusion of this history would be irrelevant to his main point, namely that Brazil should imitate Norway's isolation policies.

But Souza Araújo understood full well that couching his beliefs in historical myths was essential to the government's acceptance of isolation, which would be extremely costly and had little evidence to support its effectiveness. If Brazil's isolation program was seen as the next logical step in a history of exclusion (not to mention an imitation of Europe's "progressive" policies), and not as a radical break from the history of leprosy treatment in Brazil, isolation would be far more palatable to the government. In fact, the three volumes of government documents, photos, and scientific articles that comprise *The History of Leprosy in Brazil* should be interpreted as an indirect argument for the isolation of patients, and not merely the work of a meticulous and dedicated historical archivist (Souza Araújo, 1956).

INTERNATIONAL DECREES

Another common justification for the isolation program is that scientists were simply following international protocol, as if Brazil were a mere receptacle for scientific advancements, and not a site of dynamic research in its own right. Again, this position is supported by Souza Araújo's own writings, who exaggerated the severity of Norway's isolation program and its agency in the decline of the disease in that country. Again in "The Imparity of the Problem of Leprosy in European countries," he described the three "logical" stages of leprosy control that occurred in Norway: first, a private movement characterized by material assistance and the collaboration of doctors and benefactors; second, official medical attention; and third and "finally, after there was a considerable number of beds for the sick and the process of transmission was known, the government decreed and executed its severe measures." But in Brazil "we are practically still in the first period, that is, that of private assistance that reaches a handful of our lepers, when we should be in the final stage, that of an official prophylactic campaign." Brazil's backwardness was an embarrassment to the government and to the scientific community. In his conclusion, Souza Araújo asks for no more and no less than the implementation of Norway's national program in Brazil. "That our government imitate the example of the small and prudent Norway is what we desire. The result will be identical."

In short, this article, meant as an exhortation of the government to enact a nation-wide policy of isolation, uses all the tactics of scholarly misrepresentation that historians have identified in other countries, as well as the Brazilian preoccupation with "keeping pace" with more "modern" nations. Utilizing the political ideology popular among scientists of the time, Souza Araújo presents a situation

in which only the government has agency and responsibility; the scientists are merely advancing the knowledge to be acted upon, and the afflicted offer no resistance.

Souza Araújo was ultimately able to present his model as an imported one, giving it the caché that European and American academic ideas are still given in Brazil. In fact, some of the most noted and respected leprologists in the world, including Souza Araújo himself, were in Brazil. Moreover, the period in which the majority of the leper colonies were constructed was the “golden age” (Monteiro, 2003) of research within Brazil, and a time when leprosy isolation had largely fallen out of favor internationally. The policy of isolation that emerged from these researchers may have emulated aspects of programs abroad, but it was unique, more extensive than almost any other country, and born of specific national circumstances and paradigms.

ISOLATION IN BRAZIL

So what really drove leprosy isolation? It is important to bear in mind that public health programs are the consequence of their feasibility and costs, weighed against the perception of what are the government’s most pressing health concerns, as well as what programs will legitimize a particular government’s rule. Public health is a reflection of the relationship between a government and its people, offering perspectives on when and how a regime chooses to intervene in the lives of individuals, whether it is successful, and how it measures that success. Epidemics, mortality rates, health disparities, and sometimes chronic diseases have been taken to be a snapshot of the effectiveness and even morality of a governing body. For centuries, leprosy has provided such a perspective, and has been intimately connected with the mandate of a government to rule. In this context, we can examine the evolution of leprosy control under the colonial, Republican, and Vargas governments, and hopefully contextualize our own actions.

Almost all cases of Hansen’s disease develop after long periods of exposure to active cases of the disease. Cohabitation is generally how this happens, and usually only those with otherwise weak immune systems develop the disease from the bacteria (WHO, 2003).

As a result, Hansen’s disease thrives in poverty. After the bacteria was carried into Brazil, probably with the Portuguese colonists themselves (leprosy was still endemic in parts of Portugal) or their African slaves or both, it spread quickly in spite of its relatively non-contagious nature.

During the colonial period, the vast majority of Brazilians had no specific rights *per se*. Such conditions were acceptable; indeed, any intervention on the behalf of its citizens’ health was framed as a demonstration of the monarchy’s magnanimity. So too with the government’s leprosy interventions, the bulk of

which was a colony constructed in the center of Rio de Janeiro on royal property, in the neighborhood now known as São Cristóvão (Hunter, 2003). This colony and others like it were run by the Roman Catholic Church, which had assumed obligation to the sick, just as it had assumed control over education and other institutional functions during the period of colonization. Nuns and priests therefore tended the sick, who were afflicted with what we would call Hansen's disease, elephantiasis, leishmaniasis, and other dermatological conditions in advanced and severe stages, and, for whatever reason, could not rely on the support of their family or community. To conflate these conditions with modern-day Hansen's disease is a mistake, as the disease at this time was defined by its effects on the body, and not the biological agent *M. Leprae*.

The Portuguese brought many diseases to the colonies, and there is nothing particularly horrific about leprosy as compared to malaria, syphilis, yellow fever, or any of the several, far more deadly diseases prevalent during the monarchy's rule. The idea that all leprosy patients were rejected by their families and left on the streets seems to be more propaganda than anything else. That some historical accounts of the era write that those with what was then called leprosy were set apart probably has as much to do with the Church's propaganda of its own charity, and the prejudices of the Europeans who wrote the historical accounts, as it does with the reality of disease sufferers.

Even during the colonial period, there were conflicting interpretations of the government's duty to the health of its people. In fact, the monarchy's failure to care for the physical well-being of its subjects would galvanize the new intellectual elite that rose with the Republic. Among these was the father of Brazil's public health campaigns, Oswaldo Cruz, and the scientists that worked under him — including almost every major leprologist in the country: Souza Araújo, Belisário Penna, Artur Neiva, as well as Adolfo Lutz, who came to the Institute in 1908.

The rise of the germ theory (still controversial at the time) meant that disease could be controlled, as long as the vector of the disease was controlled. At the turn of the century, there were two known carriers of yellow fever: the *Aedes aegypti* mosquito and infected humans. Cruz's campaign focused on both sources of contagion. Those with clinical signs of yellow fever were to be maintained in strict quarantine, and federal employees were instructed in the systematic destruction of the mosquito's habitat (Stepan, 1976). Businessmen, who resented the disruption to commerce, and families of the quarantined, protested the measures and complicating the yellow fever campaign. Resentment only grew when simultaneous smallpox and bubonic plague management called for compulsory vaccination. The public resisted these interventions, according to Stepan, "because

they were uncertain of the purpose of many of the sanitary measures, because they were alienated from the government, and because they were fearful of what would happen to them.” Eventually, “special tribunals were established to force compliance with the new sanitary regulations, and the sanitary campaign was pursued relentlessly.”

More was at stake here than simply the elimination of a deadly disease. Cruz was confronted with an entrenched and deepening belief that tropical countries were inevitably diseased. Many illnesses, including leprosy, that were no longer endemic to Europe, were refashioned as “tropical diseases.” The often “racially impure” populations of these climates were also considered to be less physically robust according to evolutionary theories of this period. But the triumph of the institute could mean the possibility of modernity in Brazil, and a “modern Brazil necessarily signified a Europeanized Brazil” (de Castro Santos, 1985). In short, Cruz’s success or failure in improving the health of Brazil’s populations would either prove or disprove the possibility of civilizing Brazil. These scientists became important members of the sanitation — or *sanitarista* — movement, which unlike sanitation movements in other countries, was fundamental to the project of national identity.

By 1908, Cruz had rid Rio de Janeiro of yellow fever, and had limited success with bubonic plague and small pox. He and his colleagues had become national heroes. That Brazil’s 20th century health initiatives had their first successes in epidemic disease control foreshadowed the intrusive nature of the health system that would develop over the next four decades. Quarantine, forced medical interventions, and the separation of families are far easier to justify in a short-term situation, where those infected with the disease will presumably die or recover in a short period of time. But once these interventions had proven effective, they could be applied to diseases that did not fit the same models of incubation or transmission.

The success of the Oswaldo Cruz Institute in eradicating some diseases from the capital laid the groundwork for the tragic and misguided leprosy isolation. When leprologists looked to Cruz’s success when structuring the national leprosy prophylaxis, they transferred the paternalistic and often violent measures of epidemic control to the management of a chronic disease. The militant nature of yellow fever and other campaigns under Cruz would serve as a justification and model for the scientists who implemented them, and would later control national leprosy campaigns.

Gerhard Armauer Hansen had identified the leprosy bacillus in Norway, and published his findings in 1873 (Hansen, 2003). At the time, leprologists continued to debate whether or not the disease was contagious, and hereditary explanations

remained popular even among medical professionals well until the 20th century. Part of the confusion resulted from the fact that leprosy has a long latency period and is minimally contagious. In fact, in all the colonies of Brazil, not a single “healthy” employee is known to ever have caught the disease. Therefore, the kinds of statistical analyses that can be done with more contagious diseases like tuberculosis were not possible with leprosy. To this day, it is not clear how leprosy is transmitted, though this is often glossed over outside research circles.

At the 1897 Leprosy Conference in Berlin, the majority of the conference attendees rejected the idea that leprosy was contagious. They would not agree that it was until the 1923 conference in Strasbourg. This delay is more understandable in the context of a new and radically different paradigm of disease, and one that had several theoretical and practical problems. In the case of leprosy, *Mycobacterium Leprae* has only been partially proven to be the causal agent of leprosy according to the four postulates set down by Robert Koch in the 1880s. The bacillus, which is very slow to divide, has never been cultivated *in vitro*. Also, no one has ever been inoculated with the disease, though Hansen himself tried, without a patient’s knowledge, for which he lost his post as director of the Bergen hospital (whonamedit.com, 2007).

Though they did not agree that the disease was contagious, the delegates at the 1897 International Leprosy Conference did, however, recommend that leprosy patients be isolated from society, unless they could afford domestic isolation, indicating that there was little burden of proof on public health officials before the poor could be deprived of their rights. Meanwhile, the policy of isolation was gaining popularity in Brazil, at least among some doctors and scientists. The strongest contingent of supporters was focused at the Oswaldo Cruz institute, though according to Neiva, they remained long divided into two groups: those that favored creating a “Leprosopilis” on an island, and those that favored rural, agricultural colonies. Souza Araújo and Cruz favored the “Leprosopilis” model, but accepted agricultural colonies due to cost and feasibility concerns (Neiva, 1940a).

Adolfo Lutz led a different group of scientists, those who believed that hygiene was sufficient to stop the spread of leprosy, and that isolation was unnecessary. Based on his research linking the transmission of leprosy to the mosquito, Lutz believed that colonization of patients to be misguided. According to Jaime L. Benchimol and Magali Romero Sá, Lutz saw leprosy “with the eyes of a parasitologist,” proposing a disease model similar to that of hookworm. Lutz thought that like hookworm, it was poor hygiene, and not cohabitation, that allowed the disease to spread (Benchimol & Sá, 2003).

Lutz’s ideas of mosquito as leprosy’s disease vector never received widespread acceptance. That an eminent Brazilian scientist, however, would

question the idea of leprosy colonization was still threatening to isolationists. Artur Neiva therefore made a speech to discredit Lutz's ideas in front of the national senate in 1937. Debating with Lutz's daughter, Bertha, Neiva admitted that he could not conclusively show Lutz's theories of transmission to be false. But, he concluded, these objections were nonetheless irrelevant. Quoting Cruz, Neiva declared.

"The lack of a specific prophylaxis is not reason enough for us to behave like the Muslims, unmoved by the scourge which, little by little, expands and spreads. What is certain is that the disease is contagious. How, we do not know. But the leper is at least one of the deposits of the virus. This has been proven. Therefore, he must be isolated from the community" (Neiva, 1940a).

But another faction of scientists, whom Neiva does not mention, rejected the idea of isolation in general as unscientific and counterproductive. Among them was Eduardo Rabelo, a prominent dermatologist, who contended that isolation had already failed in other countries such as the Phillipines, and that new, more humane models were now called for. He wrote:

"I think we should have leproseria, because in this way we will manage to isolate an appreciable quantity of lepers that are poor or needy. These patients need isolation, but most of all, a place to live, sleep, and eat. There is no doubt that we should isolate lepers, but we do not have the right to practice strict isolation with a slightly contagious malady, such as leprosy is, without being able to even guarantee a cure. We would be behaving anti-scientifically, against all the international decrees, and it would be absurd to move back at this moment" (apud Serres, 2004).

This debate has been largely forgotten, both by mainstream historians and the public. In retrospect, however, such objections seem so logical, that it is difficult to reconstruct the scientific rationalizations of leprosy isolation. After all, following Neiva and Cruz's reasoning to its logical conclusion, *any* patient with *any* contagious disease should be isolated from society, whether or not the method of transmission was known.

Moreover, with a disease with a long latency period, patients who show symptoms are certainly not the only ones capable of spreading the disease. As one patient and former laboratory specialist in Curupaiti said to me, *"When the doctor told me I had to leave my home or I could infect my family, I said, 'But what about the 18 years I've spent with them? Why is it a problem now?'"* Clearly, more than scientific considerations were at play in the decision to isolate leprosy patients.

THE SANITARISTAS, VARGAS, AND THE MODERNIZATION OF BRAZIL

Those that supported the isolation of leprosy patients were *sanitaristas*, members of a political movement to sanitize, and therefore modernize, Brazil. When confronted with scientific uncertainty, their political philosophies served as the guiding theoretical force. Their belief in paternalism, the duty of the government to take control of the health of its people, and the subjugation of the individual to the collective good would all have important implications for the treatment of leprosy patients in Brazil.

Unlike the doctors of the French revolution, who believed that good government would render the hospital and the physician irrelevant, the members of Brazil's sanitary movement believed a true social revolution hinged on an expansive and quasi-independent Ministry of Health and Education. They called for a paternalistic and powerful public health department, which would have the authority to subjugate the will of individuals to the concerns of national health, and would oversee all ritualistic and cotidian practices. Meant as advocacy on behalf of the impoverished and the diseased, the ministry's violent suppression of individual rights would be justified on the basis that it was in the best interest of society. They also believed that a healthier Brazil would attract more European immigrants, who could move the economic development of Brazil forward and, undoubtedly, whiten the population. This latter policy would become an important backdrop to the rhetoric of leprosy isolation.

Scientists, whether *sanitaristas* or not, were also concerned with the legitimization and institutionalization of their own discipline. While some city-wide health interventions, such as Cruz's, had been successful, there had been no successful national policies. The various offices set up during the Republic to oversee the health of Brazilians had proven ineffective, and the once powerful intellectual class was appearing more and more irrelevant. The real organizing force behind the management of the sick remained the Catholic Church, and disease continued to have mostly mystical and not biological connotations. If the scientists were to solidify their power to create and enact policy, they would have to wrest power over disease from the Church. No battleground would be more symbolically important than leprosy.

Frustrated with the bureaucratic paralysis of the Republic, the *sanitaristas* supported Getúlio Vargas's campaign for president, aligning themselves with Brazil's greatest politician. They were consequently rewarded with positions in the government. Though support for isolation was waning in the international community, the Brazilian program thus entered its "golden age" in the 1930s. Whether or not Vargas was as alarmed by leprosy as Penna was, the goals of the isolationists were in harmony with the basic policies of the dictatorship. Vargas

sought to industrialize Brazil, and leprosy patients were seen as a threat to that program. Many of them were from the interior of Brazil, and, following general patterns of migration, were coming to the industrialized cities along the coast looking for work. These “disease-carriers” could spread leprosy to other workers, especially in factory settings. Moreover, one of the most common effects of leprosy is the loss of hand strength and fine motor control, which would have rendered them useless to the government’s industrialization program. The construction of the agricultural leprosy colonies (which Torres has pointed out echo the agricultural prisons of the era (Torres, 2003) was a way to remove the “wrong kind” of immigrant from the city.

Moreover, leprosy patients were discouraging the “right kind” of immigrant, namely Europeans, from coming to Brazil. Penna believed that this was the tragedy of Brazil’s inaction on the question of leprosy:

“It is a tremendous calamity that the politicians of Brazil have not wanted or even known how to confront [leprosy], unaware of its evils and the demoralization that it causes a country of immense territory, whose exploration and peopling needs to be achieved, in large part, by the importation of effectual foreign workers” (Penna, 1927).

Leprosy patients were thus not only a symbol of backwardness, but actual obstacles to the paternalistic, Lamarckian style of eugenics that sought to “guide” the population toward Europeanization (Stepan, 1991). Leprosy isolation may be viewed as an aspect of a larger eugenics program, largely obscured by the myth of racial democracy.

The program of isolation finally became logistically feasible under Vargas. From a politically marginal state, and with the supported of a coalition of various states that had been powerless under the Republic, Vargas’s programs were destined to have a more nationalistic nature. The dictator did away with many aspects of bureaucracy and regionalism that had choked national programs under the Republic. Instead of governors, he installed “interventors” who reported directly to him, including Artur Neiva, who held the post in Bahia. Vargas also created national record-keeping systems, built roads, and other systems of infrastructure that did not exist under the Republic. This allowed the identification and faster transport of patients — who were often captured by the sanitary police — to the more or less remote leper colonies. Finally, the stifling of the press under Vargas meant that divergent scientific ideas, criticisms of the colonies, and popular uprisings against isolation were easier to suppress (Monteiro, 2003).

Souza Araújo became director of the nation’s leprosy program, and colonies were constructed across the country. According to Eunice Weaver,

director of the orphanages for the children of leprosy patients (*preventórios*), Souza Araújo's determination forced Brazil's politicians to confront the problem of leprosy, which was discouraging the importation of Europeans "that we needed so much to supply our country with 'cultivating force'" (Weaver, 1956). With the president's sympathy, massive internment began. Weaver gushes of the president, "Sr. Getulio Vargas found in 1930 only 4 leproserias worthy of being called such, and left in 1945 no less than 22 new and modern leproserias-colonies, constructed in the Amazons, in Rio Grande do Sul and two modern Sanatoria, all with the capacity to hold more than 2 thousand of those afflicted with leprosy."

These colonies served as ideal centers for experimentation, with a fixed subject that could be punished if they said no or tried to escape. While residents in some colonies had relative freedom in other aspects of their lives, they had to submit completely and totally to the will of the leprosy doctors. The isolationists created these centers for themselves, achieving artificial control over the bacillus that they had been unable to control in the laboratory. In this vein, when he defended the program to the nation's senate, Neiva referred to São Paulo's extreme program, equating the isolation of leprosy patients with the resolution of the problem, "The leproserias of São Paulo count close to six thousand people interned," he concludes. "The problem of leprosy in the State has been resolved" (Neiva, 1940b).

Within the colonies themselves, a sort of parallel society arose, with its own rules and acceptable behaviors. Patients were separated from their families, who sometimes did not even know that their relatives were isolated. To this day, I estimate that thousands still do not know. They responded by creating new "families," a tight and protective network of residents that continues to hold these communities together. Labeled the "living dead" (*vivos mortos*), many patients were unable to cope with their new circumstances. According to current residents, many committed suicide, and some were poisoned by their own families. But it is wrong to assume that theirs are stories only of suffering. The remaining residents are a testament to the innumerable ways that humans find to survive, some petty, some heroic. The tendency to either see the colonies romantically or tragically, the lack of in-depth anthropological studies, and the lack of voices of colonial residents in academic work, have all obscured this basic truth.

Colony residents had jobs, and sometimes were forced to work. These jobs were generally positions within the hospital that the "healthy" were afraid to assume. Around 1954, the first attempt to end the colonies was made by forcing patients with medical discharges to leave in order to maintain their positions. Often unable to reintegrate into society, especially if they had the physical marks

of leprosy, the patients had no choice but to move outside hospital walls, beginning the *favelização* of the area surrounding the hospitals¹.

A superficial look at the colonies makes them appear more alike than they are. What is presented to outsiders of each of these separate societies is very similar: each one had a charity center (*Caixa Beneficente*), an internal city hall run by headed by patients, some kind of religious organization, and a prison. Each colony was divided into sick, healthy, and clean zones that were part of national policy, and which Nogueira has insightfully described. Entering the colony as outsiders, researchers are also likely to hear about and describe the elaborate cleansing rituals that took place in the colonies. No physical contact was allowed within the colonies, and whatever passed between the “sick” and “healthy” worlds had to be sanitized. Souza Araújo himself flaunted these rules, advocating that doctors not use gloves in order to make patients feel more comfortable. The total lack of necessity of these extreme measures, not to mention the humiliation that they caused residents, are even more incomprehensible, knowing that the director of the national program knew that there was no real danger. But again, these descriptions have to do with the public view presented to outsiders, which researchers inevitably are. Scratching below the surface reveals societies as different as Rio and Manaus, Teresina and Porto Alegre, or any other two far-flung cities in this country that is almost the size of a continent.

Some patients were able to reintegrate into society, but only if they could hide their past, meaning that their symptoms were not visible and they could cut ties with those who knew the truth about them. Juliane Serres has found that these former patients maintain protective, secretive networks of friendships with other ex-patients, and almost always actively guard the truth of their past. Comparing these patients with those who are recently diagnosed, it appears that the stigma is not so much from the disease, but from the fact of having spent time in a leprosarium.

Certainly the most horrific aspect of isolation, and that least addressed by governments, social movements, and academics, was the creation of orphanages for the children of leprosy patients, known as *preventórios* or *educandários*. The program was led by Eunice Weaver, an extremely important political figure who would later become the Brazilian ambassador to the UN. The *preventórios* were meant to serve as an important proving ground for both scientists and politicians, namely that leprosy was not hereditary but contagious, and that the state could better educate and “civilize” the nation’s children than their own parents. The finality of the *preventórios*, according to a report by Adalberto Mário Ribeiro, was threefold:

¹ This process is evident in Bauru, Curupaiti, and Tavares de Macedo, among other hospitals.

a) “prophylactic,” allowing vigilance over children likely to develop the disease; b) “social,” assisting those who would have become sick and then carriers of the infection; and c) “scientific, since the child who is interned in the *Preventório* becomes an excellent field for observation and study. We can therefore surprise leprosy in its nascent state, and follow its progress, permitting the realization of interesting studies, such as have been conducted already in São Paulo (Ribeiro, 1944).

The *preventórios*, however, fell into abandonment, especially after Eunice Weaver left, and were the sites of horrific abuses, physical, sexual, psychological, and chemical. The policy of experimenting on children allowed permissiveness in the use of drugs to control these “orphans,” and the employees had a large range of freedom to punish and abuse these children as they saw fit.

Those that I have interviewed about their experience suffer from serious psychological damage rooted in their experience, deepened by the shame that they still feel in speaking out. Many cannot be called fully-functioning adults. The policy of separating children from their sick parents continued until at least 1983 in parts of Brazil. When children were allowed to return to their parents, the parent-child relationship was largely destroyed, both by the physical separation and the psychological brainwashing that would not allow the “sick” to connect to the “healthy,” throwing these communities into chaos. This chaos has destroyed the normal parent-child and grandparent-grandchild relations that are so essential in Brazil’s poor communities for the protection and education of children. These younger generations are largely infantilized and do not know how to live outside the colonies without the minimal support they receive from the government. Though the colonies were officially opened between the 1950s and 1980s, they have failed to become communities.

CONCLUSION: THE FAILURE OF ERADICATION AND THE POSSIBILITY OF A DIFFERENT FUTURE

The government of Brazil has done some publicity regarding Hansen’s disease, and the World Health Organization supplies free antibiotics. Similar policies have worked in other countries, and the failure of Brazil to eradicate Hansen’s disease has baffled many. This, I believe, is because the government and the WHO have neglected a powerful group of experts, namely residents of the colonies, who often know more about the disease than their own doctors. These patients not only have had leprosy for many years, but have lived with sufferers of the same disease, and in many cases have assisted and continue to assist their neighbors in a medical capacity. They often reject what doctors tell them, and are considered “difficult” patients. Several doctors employed within the colonies try to avoid seeing them.

These residents reject almost across the board the idea of a “cure,” which health workers often consider to be pure ignorance. But it is understandable that a patient, who has finished taking antibiotics two decades earlier, and must have a foot amputated, would not consider himself cured. Moreover, patients are keenly aware that if they are cured, they are no longer entitled to any government assistance, regardless of what else they have suffered.

Returning to Artur Neiva’s speech, we find an ominous forecast of the problems that Brazil faces today in its fight against leprosy. Though Neiva never directly addresses the issue of popular resistance to colonization, he does so indirectly by quoting his former boss, Emilio Ribas. Ribas, director of São Paulo’s health ministry (*Serviço Sanitário do Estado de São Paulo*), who oversaw the construction of the nation’s first modern leprosy colonies, wrote:

“Whatever gives the idea of degradation or of imprisonment is counterproductive to the prophylaxis [of leprosy], principally the fetishism of an island, since insular isolation would provoke immediate reaction and the occultation of the sick” (apud Neiva, 1940a).

Ironically, it is precisely this problem which has made the leper colonies such a spectacular failure in Brazil. The degradation, imprisonment, and misinformation of the sick have led older patients to be wary of eradication, and even find it personally threatening. That the patients themselves had no voice in policy 70 years ago allowed for their imprisonment, and their exclusion from policy measures today challenges the core of the nation’s interventions.

It is my hope that the residents of the colonies will in the future be considered central to the eradication of Hansen’s disease, rather than peripheral to the government’s efforts. Brazil should recognize the sacrifices they and their families have made, which have allowed scientists to experiment with disease transmission and cures. Moreover, these patients could be the most effective health workers because of their familiarity with the disease and status as experts among the sick. Bringing their children into the disease program, and allowing them the flexibility to make it more relevant to the lives of old and new patients, would help the government redirect its efforts. The sick and their children could thus rediscover their own agency, and begin a new chapter in the history of Hansen’s disease.

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