

## **Leprosy and Stigma in the Context of International Migration**

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*Summary* If it can be argued that no single attribute or condition (leprosy included) is inherently or universally considered to be ‘deeply discrediting,’ to quote Goffman, then we must consider how external factors shape stigma associated with that condition in different cultural and socioeconomic contexts. Often, an analysis of what is perceived to be stigma towards people affected by leprosy uncovers other prejudices or stigmatising attitudes associated with class, gender, and/or ethnic inequalities in that society. The movement of people across international borders adds new dimensions to the experience of leprosy, as affected individuals confront different sets of understandings of the disease among healthcare professionals, friends, family, and employers in host and sending countries. Preconceptions of the immigrant ‘other’ in host countries may be bound up with notions of disease and danger, further complicating the experience of leprosy treatment for immigrants. Drawing on the work of others and on early stage qualitative research on leprosy among Brazilian immigrants to the United States, this paper will consider the ways in which immigration and transnational processes could affect the experience of stigma among immigrants affected by leprosy.

### **Introduction**

People are very afraid. You can’t be talking about it because people - friends will be afraid; friends, even people with whom you have close friendships, say, “Wow, this is contagious? Wow, you can’t work in Americans’ homes.” (Mauro<sup>1</sup>, age 55)

On the surface, this quotation, from a first generation Brazilian immigrant in the United States who recently completed treatment for leprosy, seems to be a classic example of stigma in the sense of negative associations with a condition that is ‘deeply discrediting,’ to quote Erving Goffman.<sup>1</sup> However, there is a subtext that demonstrates the complexities of ‘leprosy

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<sup>1</sup>All names of interview participants are pseudonyms.

stigma' in the context of international migration and of the concept of 'health-related stigma' in general. By 'Americans' homes,' he was referring to his own experience working in housecleaning, a common profession of many Brazilian immigrants to the U.S. His Brazilian friends' comments were not necessarily about their own fears or stigmatising attitudes about leprosy but about the potential discrimination that he might experience from American employers, who they assume (perhaps correctly) will know little about the disease. Their suggestion might also be based on fears about the precariousness of the job market, particularly for undocumented workers, and assumptions about North American attitudes about immigrants from Latin America. In the same interview, Mauro stated that he did not tell 'Americans' about his disease for fear he 'would be deported.' As Scambler<sup>2</sup> has written, "the disadvantage sometimes accruing to those regarded as shameful through stigmatization is more often than not mixed in with, even secondary to, exploitation and oppression," such as that experienced by some immigrant minority groups in the United States and elsewhere.

Even as leprosy incidence worldwide slowly decreases, the movement of peoples around the globe is accelerating. According to United Nations estimates, there were approximately 214 million international migrants (those living in a country different from that in which they were born) in 2009; this number is "greater than at any time in history."<sup>3</sup> Immigrants were "projected to account for 10 per cent of the population residing in the more developed regions, up from 7.2 per cent in 1990,"<sup>4</sup> a much higher percentage than projections for what the U.N. calls 'less developed' and 'least developed' regions (1.5 percent and 4 percent, respectively). Although the movement of people affected by leprosy is certainly not a new phenomenon, in analysing and addressing 'leprosy stigma', it is important to be aware that prevailing attitudes about immigrants, differential knowledge about leprosy in host and sending countries, and transnational practices, among many other factors, influence how this stigma manifests.

In this article, I draw in part on preliminary research<sup>ii</sup> on transnational health practices and leprosy and on the work of others to suggest several factors that could complicate 'leprosy stigma' or that require us to deconstruct the concept of stigma altogether in order to provide practical solutions to the challenges that migrants with this disease might face. In this article, the focus is mainly on global South to North migration. In 2009, I led one focus group<sup>iii</sup> with two men from Brazil and one from Mexico and interviewed one man originally from Vietnam, all currently living in the metropolitan Atlanta area. The Brazilian men, 'Mauro', 55, and 'Waldir', 47, were both from low-income families in Brazil and had emigrated from Goiás and Minas Gerais states, respectively, in 2001. They worked in a variety of jobs in the Atlanta area, including housecleaning. The Mexican man ('Juan', 57) was from Nuevo León state and had also lived in the United States for several years and worked in construction with his sons. All three men had come to the U.S. to follow adult children who had already made the trip. I also did an individual interview (with a translator present) with one man, aged 66, who was originally from southern Vietnam and had worked as a cook in a restaurant in Atlanta until disabilities associated with leprosy made it difficult for him to continue. He had come to the U.S. nearly 22 years prior to our interview. Through contact with one clinic in the Atlanta area, I have met several other first generation immigrants in treatment for leprosy. This handful of preliminary interviews have highlighted

<sup>ii</sup>This research has been approved by the Institutional Review Board of Georgia State University in Atlanta, Georgia.

<sup>iii</sup>This focus group was organised in conjunction with Lauren Myers and Dr. Diane Harper, current graduate students at Emory University. The group was facilitated by Dr. Carlos Franco-Paredes of Emory University Hospital.

some of the unique features of the experience of outpatient treatment for immigrants in the 21st century. Through this research, I have also paid close attention to media and political discourses that draw on public perceptions of leprosy to promote anti-immigration agendas.

#### THE STIGMA CONCEPT

In Goffman's classic analysis of stigma, he was clear that negative associations with a particular attribute were relative to social relationships and circumstances, so that any given 'attribute' is "neither creditable nor discreditable as a thing in itself."<sup>5</sup> However, as Weiss, *et al.*<sup>6</sup> have pointed out, his assessment of stigma was couched in the language of the sociology of the 1960s; Goffman used deviance from the norms of Western society to explain many stigmatising attitudes. Since Goffman, several researchers have elaborated on and contextualised the concept of stigma to demonstrate how historical processes, cross-cultural differences, and structural inequalities can affect how stigma is constructed. In an important article that called simplistic notions of stigma into question, Richard Parker and Peter Aggleton<sup>7</sup> called for an approach to stigma that emphasises "the relations of culture, power, and difference." In using the phrase, "the experience of stigma," I refer to a multilayered phenomenon that involves discrimination, exclusion, marginalisation, and lowered self-esteem; negative associations or beliefs about a particular status or condition within a particular culture play a role in how stigma is experienced, but stigma is 'multilayered' because any given stigmatising belief is usually linked to and compounded by other beliefs and other societal inequalities.

Anthropologist James Staples, in his research in South India, has noted that leprosy stigma is often used as a "catch-all explanation for socially negative reactions that are more complex in origin;" it is a concept used by healthcare workers, aid agencies, and people affected by the disease as "a convenient shorthand explanation for a range of more complex social issues."<sup>8</sup> In research I conducted in the late 1990s on patient experiences with contemporary outpatient treatment for leprosy in Rio de Janeiro, I found that nearly every case of what was described as stigma or *preconceito* (usually the term equated with stigma or prejudice in Brazil) by people affected by the disease was not about others knowing they had 'leprosy' but about the difficulties they experienced as an indirect result of their illness within the socioeconomic and cultural context of their daily lives.<sup>9</sup> Many isolated themselves from friends because of concerns about appearance (often from medication side effects) but most received emotional support from their families. Only one man [of 41 people I interviewed who were in treatment] said that most of his friends and family separated themselves from him when he became very sick with repeated episodes of leprosy reaction. Although his isolation was a consequence of having leprosy, none of his relatives actually knew what his diagnosis was. He acknowledged that the underlying cause of his abandonment by others was not his illness but his inability to work and provide economic support for others as he once had. He had previously worked in the informal economy, selling merchandise door-to-door, and when he could no longer work, he had no back-up income.<sup>10</sup> His physically demanding job, in which he had to hike up hilltop favelas with merchandise daily, may have triggered or exacerbated the extreme physical problems he had with leprosy reaction; loss of income plunged him into even deeper poverty and affected interpersonal relationships.

Understanding stigma as a process "linked to the reproduction of inequality and exclusion"<sup>11</sup> is important when focusing on people who are moving across borders, particularly those moving from developing or newly industrialised nations to wealthier

nations. International migration creates circumstances that complicate the experience of illness and the perception and experience of stigma. Some of these circumstances, such as access to treatment options or stigmatising beliefs about leprosy, are not unique to international migrants; however, the compounding factors (such as anti-immigration sentiment, language barriers, and limited social or cultural capital in the host country) might be different than those faced by people in their countries of origin. Below I suggest several factors related to immigration and transnationalism that might work in conjunction with leprosy to result in social exclusion, discrimination, and lowered self-esteem.

#### ANTI-IMMIGRATION SENTIMENT, RACISM, AND ETHNOCENTRISM

Negative stereotypes that exist in the host society about people of particular nationalities or ethnic identities may negatively influence migrants' experiences with disease treatment in that country. Generalised anti-immigration sentiment during a particular historical era may also influence perceptions of immigrants affected by infectious disease. Disease has been used in past and contemporary contexts to highlight and exaggerate the supposed dangers of the 'other.' Gussow<sup>12</sup> suggested that stigmatising beliefs about leprosy as a moral or spiritual punishment had little to do with the creation of leprosaria during the late colonial era. Instead, racism, ethnocentrism, and general Western fears of non-Western peoples in colonial territories controlled by Europe and the United States featured prominently in leprosy confinement policies and control of 'foreign' populations.

In the current era, disease has been a common theme in media and political tirades in Europe, North America, and other wealthier nations that are destinations for much of the migration of peoples from emerging or developing nations. Farmer<sup>13</sup> has demonstrated how racism factored in to popular and biomedical associations of Haitians and Haitian immigrants to the United States with HIV/AIDS, tuberculosis, and other infectious diseases throughout the 20th century. In a recent article in *Leprosy Review*,<sup>14</sup> I gave examples of distortions of leprosy statistics by the mainstream media in the United States in the past decade, seemingly in an effort to fuel panic about 'illegal' immigration. When leprosy is presented by media sources as dangerous, highly contagious, or out of control in a country where it is rare, it is most likely being used a foil for racist or xenophobic attitudes. A glaring example in the United States was the 2005 reporting, on CNN's *Lou Dobbs Tonight*, of misinformation from an unreliable, non-peer-reviewed journal source about leprosy incidence in the U.S. (claiming 7,000 new cases in a recent 3 year period); Lou Dobbs offered no retraction, apology, or admission of error when his data into question on the programme *60 Minutes*.<sup>15</sup>

Local, national, and global economic processes that result in job loss and economic troubles for a nation's working and middle class may result in heightened scapegoating of immigrant populations, as was evident in Dobbs' report and in news reports of a leprosy 'epidemic' in Arkansas in 2008 among Marshallese [legal] immigrants, which turned out to be about nine reported cases. A number of anti-immigrant blogs in the United States posted this story, often focusing on the loss of jobs by Americans to the dangerous and 'unclean' Marshallese,<sup>16</sup> who were emigrating to Arkansas primarily to work in the Tyson poultry factories in that region.

Mention of leprosy, along with other diseases, continues to pop up in the media in the U.S., in association with immigration; in a December 2010 radio broadcast of *The Savage Nation*, a nationally-syndicated radio programme, right-wing host Michael Savage linked New York's bedbug infestation to border insecurity and went on to mention leprosy as a

disease that might become a serious problem if the borders were not controlled and immigrants not screened. In a probable reference to Dobbs' misreporting about leprosy, he said, "I know what I'm talking about. I'm not a TV host. I'm a trained epidemiologist."<sup>17iv</sup> - Although these distortions of information about leprosy could result in discrimination against those who are affected by the disease in the U.S., the intention is rather to use leprosy to stigmatise immigrants, rather than the other way around. In addressing problems that people affected by leprosy might have in the context of international immigration, local and national ideas about immigration and about immigrants from Africa, Latin America, and Asia must be taken into account.

#### DIAGNOSIS, EXPLANATORY MODELS, AND LANGUAGE

The circumstances of immigration and the combination of social, cultural, and linguistic barriers between healthcare workers and patients can generate increased difficulties in diagnosis and general communication about illness and treatment. Physicians and healthcare workers in host countries should be aware of the potential meanings and explanatory models<sup>18</sup> of leprosy and conceptions about the body and health in general of leprosy for patients from different cultural backgrounds before giving a diagnosis. In practice, however, physicians in nations where leprosy is rare may carry their own beliefs about leprosy that do not match with the current biomedical model. They may reinforce beliefs that patients bring with them about leprosy or introduce stigma where it did not previously exist.

In Brazil, with over 33 former leprosy 'hospital-colonies,' many of which are still inhabited by former patients and their families, the idea of mandatory isolation of people with leprosy still present in the minds of many Brazilians.<sup>19</sup> This set the stage for Mauro's fears upon receiving a diagnosis:

"Regarding stigma (*preconceito*) for me, I remember, when I was a child, my mother had a close relative, her cousin, in Goiânia, the city where we lived - it had a town - it was so stigmatizing [*preconceituoso*], that it had programmed days for visits, depending on the state of the person, you could visit them. And I went several times with my mom when I was a child. This was 45 years ago, but the stigma was great. Those who were there were totally removed from society, hidden there to receive their treatment."

His experience in receiving a diagnosis of leprosy in the United States brought back his memories of past policies of isolation. He said of the dermatologist in Georgia who gave him the diagnosis: "because of her own misunderstanding, she terrified me and said that there was no treatment and that I needed to be in the ICU, in observation, with no contact with other people. She was a [*pavorosa*—fearmonger]." With the 1999 closing of Carville, the last community for people affected by leprosy in the continental United States, and with WHO pronouncements of leprosy's imminent global elimination, it may be less likely that U.S. physicians would consider leprosy as a possible diagnosis. It is worthwhile to consider that in nations where prevalence of leprosy is very low and has historically been low, knowledge about leprosy's early symptoms, level of contagion, or curability may also be low. This could result in unnecessary actions on the part of medical practitioners that could generate stigma for patients. Lack of knowledge could also result in misdiagnosis and other forms of delay in

<sup>iv</sup>His background is, interestingly, in anthropology and ethnomedicine.

the initiation of multidrug therapy. After diagnosis, Mauro's treatment was further delayed as his dermatologist tried to gain information on how he could receive free treatment. Mauro, meanwhile, contacted friends and physicians in Brazil and had medications sent through the mail.

The terms used to describe a disease in different languages and cultural contexts can have an impact on whether or not or how stigma is constructed. One man with whom I conducted an individual interview, who was in his mid-sixties, came to the United States from Vietnam over two decades ago. Our interview was conducted via a translator with the man's wife present. He said he was unfamiliar with the disease before he was diagnosed in the United States. He knew of no one else in his family with this disease, and he said he was not aware of any stigma associated with it in Vietnam. It may be that he did not associate his illness with leprosy because of terminological differences in the use of the term Hansen's disease in the United States or in the difficulty of translating the term. Perhaps because of this, he did not self-stigmatise or suffer a loss of self-esteem directly associated with leprosy, although he was forced to retire early because of disabilities associated with the disease. Similarly, Juan, from Mexico, did not seem to connect his disease with anything of a stigmatising nature; he believed he acquired his illness, Hansen's disease, after exposure to tiny organisms (*animalitos*) that were in insulation that fell on him during a construction job in the United States. His family members and others in the Mexican community in Atlanta knew about his disease, but it was unclear if they knew it was 'leprosy,' and he had never experienced stigma other than comments or concerns about redness on his arm.

Although the above examples have to do with beliefs and understandings about leprosy, the circumstances of the delivery of information about leprosy is related to wider global processes. The fact that people are facing diagnosis in a setting where their language skills are not strong (as was the case for all four participants I have discussed here), where they are not yet citizens, and where their access to the healthcare system might be limited can be understood as a product of the push/pull factors that resulted in their immigration to the U.S. in the first place.

#### RESOURCES IN HOST REGIONS

Brettel<sup>20</sup> has noted that the experiences of an immigrant group vary widely depending on the city or region to which they migrate, even within the same country. Transportation options, employment opportunities, healthcare availability, and cultural/ethnic makeup of an urban or rural area can all affect the experience of immigration and may directly or indirectly affect the experience of illness for immigrants. The presence of a community of people of the same national background could provide social networks and a support system, though preconceived ideas about the disease within that community might also be present. For the Brazilian men I interviewed, social networks in the extensive Brazilian American community in north Georgia were vital in providing information about where and how to receive treatment for leprosy. Both of these men reported knowing other Brazilian immigrants affected by the disease who were able to refer them to a location for treatment.

The availability of medical treatment for leprosy may be regional. In the United States, ambulatory clinics for leprosy exist in 11 cities.<sup>21</sup> In other parts of the country, physicians may not be aware of resources they can access for treating patients, though this information is accessible via the National Hansen's Disease Center's website, and treatment can be coordinated with local physicians. Access to treatment in the early stages of leprosy is



important in terms of preventing complications that could lead to changes in appearance and disabilities, which could lead to self-stigmatisation and enacted stigma. Visible problems or skin problems could affect employment opportunities for immigrants in particular. Although this was not the case for the men I interviewed, who had little direct contact with native-born American employers, this is theoretically a source of stigma that would also not simply be about leprosy but about the circumstances of and local/national perceptions of international migration.

## **Conclusion**

In a recent article in *The Guardian*, Yohei Sasakawa<sup>22</sup> pointed out several reasons why those affected by leprosy should not be stigmatised, including the fact that “the first dose of MDT kills 99.9% of the bacteria that causes leprosy, rendering the person no longer infectious.” While this is important basic information that should be made available globally, the public education approach assumes that ‘leprosy stigma’ is about lack of knowledge about leprosy - that it is solely about misunderstandings about its transmissibility, curability, and symptoms. Information about leprosy is readily available online on websites of the World Health Organization and the U.S. National Hansen’s Disease Program, yet those who have a particular agenda choose to ignore or distort the information that is available. In the current xenophobic climate of the global North, it is important to be cautious about revealing the simple fact that that a small number of immigrants may be affected by leprosy, as this can be (and has been) used as a tool to further anti-immigration agendas. On the other hand, public education about leprosy’s curability and low transmissibility in both endemic and nonendemic nations could be useful in helping the general public in these nations to dismiss politically motivated attempts to portray immigrants with leprosy as a threat a nation’s safety.

Globalisation, immigration, and transnationalism are not new phenomena, nor has it been only in the 21st century that people have experienced leprosy and its treatment in the context of migration. However, through greater ease of movement and through the internet and other media technologies, globalisation has taken on new meanings. Here I have presented just a few examples of the experience of leprosy for immigrants in the contemporary context. The complex nature of what is often described as ‘stigma’ as it relates to the immigrant experience of leprosy also allows us to further explore stigma in other contexts. We might attempt to view stigma much in the way that contemporary anthropologists understand culture - as a fluid and multilayered phenomenon. We must look deeper at individual incidents that are understood as stigmatising and at the narratives of those affected by the disease to determine what factors are working to complicate people’s lives or to deepen an individual’s social and economic exclusion.

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