Iatrogenic stigma in outpatient treatment for Hansen’s disease (leprosy) in Brazil

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Abstract

This paper explores how iatrogenic stigma, or stigma that is produced through a patient’s encounter with physicians or with biomedicine in general, might emerge in outpatient treatment for Hansen’s disease, or leprosy. Based on in-depth interviews with people affected by Hansen’s disease and observations conducted at several public health clinics in Rio de Janeiro, Brazil, this research identified several aspects of the biomedical encounter that generated or contributed to stigma, either felt or enacted. Also noted in the research were positive examples of techniques used by physicians and health care workers for minimizing or circumventing stigma. The paper touches upon several topics, such as culturally mediated responses to medication side effects and communication between health care workers and patients, that might be salient or useful for health educators and others who are attempting to reduce health-related stigma.

Introduction

Social scientists writing about stigma tend to focus, correctly, on the way cultural models of the body, health and illness determine whether or not a health-related condition will be perceived as ‘deeply discrediting’ [1, p. 3]. In more recent studies, social scientists have expanded their investigation of stigma and culture by looking at how gender roles, class structures and local constructions of race and ethnicity affect attitudes toward health problems [2, 3]. Often when researchers discuss ‘culture’ in relation to health-related stigma, they are writing about the shared knowledge and behaviors of a population affected by illness. There is another set of behaviors and beliefs that has a strong influence on patients’ experience of illness—that of the biomedical realm. In the contemporary context, most people around the world have at least marginal access to biomedicine as a treatment. Patients’ interactions with biomedicine and its representatives strongly influence how they experience and understand their bodies and their illnesses. The biomedical encounter remains a relatively unexplored space of stigma generation, particularly in the realm of infectious disease treatment.

This paper analyzes sources of iatrogenic stigma, or stigma that emanates from the biomedical encounter, in outpatient treatment for leprosy, or Hansen’s Disease, in the city of Rio de Janeiro, in this paper, I primarily use the term Hansen’s disease to refer to the disease caused by infection with the bacillus Mycobacterium leprae. Hansen’s disease is named after Gerhard Hansen, the Norwegian scientist who, in 1873, first identified the bacillus under the microscope and who first associated it with leprosy transmission. The decision of whether to use Hansen’s disease or leprosy in writing about the disease is a difficult one, but as Hansen’s disease (hanseníase) is in standard use in Brazil, I have chosen to use this term here. I use the term leprosy and its derivatives
primarily to refer to historical uses or popular concepts of this disease.

After a brief summary of the history of the relationship between stigma and biomedical treatment for Hansen’s disease, I describe the different areas that I have observed as sites or potential sites for the generation of stigma in outpatient treatment. I also include positive examples of effective interventions and actions in which healthcare professionals I interviewed and observed in Brazil sought to address stigma-related problems or to prevent the generation of stigma within the biomedical setting. The presentation of this information is intended largely as food for thought for policymakers and healthcare professionals who work with Hansen’s disease and other health-related conditions in terms of taking a more holistic view of where stigma originates, how it affects patients in different ways, and how it might be addressed.

In focusing on iatrogenic stigma in this paper, I am not discounting the significance of other forms of societal stigma that may affect treatment-seeking behavior, adherence to treatment and overall patient experience. Societal stigma spills over into the medical encounter as well, influencing public health policies and affecting attitudes of biomedical representatives. In Brazil, biblical understandings of Hansen’s disease (or leprosy—*lepra*) as a shameful and spiritually polluting condition still exist in the public imagination and may be perpetuated in some Catholic Sermons. Protestant Evangelical Churches, increasingly popular among the working classes, frequently suggest that diseases that require complicated treatment may be the result of demon possession and that faith healing, rather than medical treatment, is the only effective cure. Ideas of Hansen’s disease as highly contagious and disabling create problems for patients in Brazil in their family, community and place of employment. Elsewhere [4], I have discussed some of the popular cognitive models of Hansen’s disease in Brazil that may influence patient behavior and self-stigmatization. Identifying and understanding culture-specific forms of stigma associated with Hansen’s disease continue to be vital in terms of improving patient experience and eliminating the disease. It is especially important for biomedical representatives to be aware of how the treatment experience, within the particular culture in which they are practicing, might interact with and exacerbate pre-existing stigmatizing attitudes.

From confinement center to outpatient treatment: iatrogenic stigma and Hansen’s disease

The word ‘iatrogenic’ comes from the Greek roots *iatros* (physician) and *genic* (induced or produced by) [5]. In a brief but thought-provoking editorial article in the *British Medical Journal*, Sartorius [6] described iatrogenic sources of stigma generation associated with mental illness. He discussed how practitioners construct and reproduce stereotypes of mental illness through their discourse about patients and their conditions. He also mentioned how medications can result in physical and behavioral side effects that ‘will mark the person as having a mental illness more than the original symptoms of the illness did’ [6, p. 1470]. Although Hansen’s disease is quite different from mental illness, there are many parallels in terms of how iatrogenic stigma emerges in each.

Historically, Hansen’s disease stigma and biomedicine are closely linked. Gerhard Hansen’s proposal that the *M. lepra* bacillus was the etiological agent of leprosy ushered in a second wave of leprosarium openings around the world. The first wave, in Medieval Europe, was prompted by a mix of medical and moral religious beliefs and fears about Hansen’s disease and its supposed carriers, although forced confinement in leprosaria may have also been a means of political and social manipulation of the working class by those in power [7, 8]. Similarly, in the 19th century, medical theories about Hansen’s disease transmission were charged with political and historical overtones. Biomedical policy merged with colonial paradigms of the non-Western ‘other’. For Europeans, Hansen’s disease (as leprosy) ‘dramatically externalized anxieties about living in tropical climates and
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mixing with people of others races’ [9, p. 25]. As Gussow [10] has suggested, isolating patients was presented as being both an important public health measure and as beneficial for patients’ health. In reality, it served more to quell the fears of those in power and functioned as a form of social control of populations perceived in the West to be ‘dangerous’ and ‘disease-ridden’, such as those living in colonial territories. The result of having multiple leprosaria in endemic nations was that Hansen’s disease, already feared and associated with contagion and moral transgression, acquired the added stigmatizing association of forced isolation, and in turn, these centers for treatment became stigmatizing in themselves.

In the 1940s, US researchers discovered the effectiveness of sulfone-based drugs in killing Hansen’s disease bacilli, thus rendering patients non-contagious. By this time, it was already known that there were different forms of Hansen’s disease and that not all people affected by Hansen’s disease transmit the disease. Despite this breakthrough in treatment and despite a more complete biomedical understanding of Hansen’s disease, many leprosaria worldwide continued to admit resident patients until the 1970s. Disease treatment during this time period involved monodrug treatment with the sulfone-based drug dapsone, and many patients had to take this drug throughout their lives to control the profusion of bacilli in the body. Biomedical justifications for the policy of patient internment included the chronic nature of Hansen’s disease monodrug treatment and the idea that patients should be continually monitored to prevent disabilities. Still, national and state public health policies and federal laws regarding reporting cases and isolation of patients served to perpetuate stigmatizing attitudes about leprosy that generated unnecessary stigma and fear in the general public and in communities where people were diagnosed. In 20th century Brazil, public health officials modeled Hansen’s disease policies and leprosarium design on those of the United States, particularly looking to the Hansen’s disease confinement and research center in Carville, LA [11].

In 1985, the World Health Organization (WHO) established a multidrug therapy (MDT) program that made leprosy treatment more effective and of shorter duration. Today, the pharmaceutical company Novartis, in conjunction with WHO, provides MDT free of charge and on an outpatient basis. The duration of treatment and medications used in leprosy treatment today depend on the type of leprosy with which an individual is diagnosed. Patients diagnosed as ‘paucibacillary’ (literally, ‘fewer bacilli’) receive 6 months of treatment with a combination of the drugs rifampicin and dapsone; multibacillary patients receive 12 months of treatment and a combination of rifampicin, dapsone and clofazimine. Patients receive plastic and foil ‘blister packs’ of pills to take home with them for daily dosages, but they must also come in once a month to take a supervised dose of rifampicin, receive their next month’s blister pack and undergo a physical exam [12].

Although patients who have completed MDT are considered ‘cured’, some experience complications associated with the body’s immune response to decaying leprosy bacilli in the body; the associated symptoms, known as ‘leprosy reaction’, are often similar to the symptoms of leprosy itself and can occur before, during or after treatment is complete, so for some, treatment, most commonly with the steroid prednisone or the potentially teratogenic drug thalidomide, may continue for years after MDT is complete and the patient is cured.

The advent of MDT as a highly effective treatment over dapsone monotherapy has made huge strides in terms of reducing the prevalence of leprosy worldwide and preventing many of the severe deformities and disabilities associated with the disease. These changes have also been significant in reducing stigma associated with the disease, but there are still several aspects of the MDT program, as implemented in Brazil and elsewhere, that contribute to stigma that is perceived/self-imposed (‘felt’ stigma) by patients or imposed by others in a society (‘enacted’ stigma) [13]. Van Brakel and Bakirtzief [14] listed ‘research on the impact of MDT’ as one of the top priorities in their summary of a meeting to determine the most important social science research foci relating to stigma at the most recent International Leprosy Congress, held in Salvador, Brazil.

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Methodology

The observations presented here are based on ethnographic research conducted in the city of Rio de Janeiro during 11 months in 1998–99 as well as on follow-up research and conversations with physicians and Non-Governmental Organization (NGO) workers on subsequent brief visits to Brazil (in 2002, 2004, 2005 and 2006). The original research project focused on cultural and socio-economic aspects of outpatient treatment for Hansen’s disease and included observations of interactions between health care workers and patients in outpatient treatment centers for Hansen’s disease; participant observation in educational meetings about Hansen’s disease and self-help group meetings for people affected by the disease; in-depth, open-ended interviews with patients and interviews with health care workers and volunteers who work with Hansen’s disease.

I observed different aspects (including diagnostic testing, administration and explanation of medication, physical therapy instructions and patient counseling) of the clinic visits of a total of 144 individual patients at five health posts that served as referral centers for Hansen’s disease in the greater Rio de Janeiro metropolitan area. I spent the majority of my time at one of these referral centers that was also a medical research center and that served much of the working class population of the Zona Norte (North Zone) of the municipality of Rio and the suburban satellite cities of the region to the north of the city known as the Baixada Fluminense, where Hansen’s disease prevalence was quite high relative to other areas of Brazil. For example, in 2000, there were 8.8 cases per 10,000 inhabitants in the Baixada Fluminense municipality of Queimados [15]. All but one of my interviews with patients was conducted at this clinic, in an empty examination room or in a classroom in a nearby building. One individual who was a patient at this clinic asked that I interview her at the offices of an NGO where she volunteered.

I conducted interviews with 41 individuals who were in different stages of treatment for Hansen’s disease, including some who had completed treatment, and with two individuals who were in the process of undergoing diagnostic testing for Hansen’s disease but whose cases were unconfirmed. A total of 19 men and 24 women were interviewed. The majority of patients interviewed, 86%, was between 20 and 50 years of age. Most came from favela (shantytown) or other low-income neighborhoods, and the majority worked in service professions (most commonly, domestic work and manual labor for women and men, respectively). Patients were selected through a convenience sampling method, drawing on individuals who were willing and had time to sit for a 1- to 2-hour interview after their clinic visits. Although there is bias in this type of non-probability sampling technique, the information collected from these interviews was very useful in conjunction with several other forms of ethnographic data collected during 11 months of fieldwork in Brazil. I am fluent in Brazilian Portuguese, so no translators were used for these interviews. I obtained written consent from each individual, and consent forms were also explained orally to each participant. Interviews were (audio) tape-recorded and later transcribed. Patients were very forthcoming in their interviews, and most seemed eager to tell me their stories. I was able to elicit detailed ‘illness narratives’ [16] that included patients’ experiences with Hansen’s disease from the appearance of first symptoms up to the time of the interview. The seven-page interview schedule I used contained questions on patient background (including age, profession, marital status and neighborhood of residence), first recognition of symptoms, steps taken to seek a diagnosis, family and work situation as they relate to Hansen’s disease, treatment side effects, alternative treatments used, problems with leprosy reaction, feelings about their medical care and other concerns (besides Hansen’s disease) of everyday life in their communities. I also conducted in-depth, tape-recorded interviews with 14 individuals who work with Hansen’s disease patients or patient issues (including physicians, nurses, psychologists, social workers, physical therapists, NGO volunteers and one city health official). These interviews were tailored to each individual, most of whom I knew well after months.
of working closely with them before I conducted formal interviews.

I attended eight ‘educational meetings’ or ‘waiting room’ meetings at two different outpatient clinics; in these meetings, health care professionals (social workers, psychologists or nurses) would provide information about the causes, complications and treatments for Hansen’s disease and would discuss popular beliefs and misconceptions about Hansen’s disease that might result in stigma. Hansen’s disease patients and patients waiting to be seen for other health problems were encouraged to participate and ask questions. Self-help group meetings I attended (two total, at one clinic) were directed by an NGO volunteer who had experience in psychology and were intended specifically for Hansen’s disease patients to be able to talk about social, emotional or physical problems that they were having with the disease or the treatment, although non-patients could also attend. I took fieldnotes during or immediately after these meetings and participated in discussions when relevant.

In addition to my fieldwork in outpatient clinics, I spent time with members of an NGO who work with Hansen’s disease education and patient advocacy, attending some of their educational campaigns and reviewing records of telephone inquiries received about Hansen’s disease. Also, on four occasions, I visited a public school adjacent to a favela, where I had a chance to ask groups of parents of school children about their understandings of Hansen’s disease/leprosy. After gathering this information on ‘folk models’ or popular cognitive models about the disease, I gave brief lectures in Portuguese about the biomedical model of Hansen’s disease and about self-detection.

All field notes and interview transcriptions were manually coded by topic for later content analysis. Although I did not have a sample size large enough to conduct significance tests, I generated statistics based on similarities I noted in patient narratives (in terms of percentages of interviewees who complained about certain medication side effects, who received a misdiagnosis of their condition, for example). Sentiments expressed by patients in qualitative interviews were compared with other data forms collected and with research conducted by other Brazilian social scientists who worked with Hansen’s disease patients in Rio de Janeiro and elsewhere [17, 18]. In 2002, I attended the Sixteenth International Leprosy Congress, held in Salvador, Brazil, where I was able to meet Hansen’s disease researchers and former patients from all over the world and from other parts of Brazil, which provided me with more information for comparison with my own data. A ‘Health-related Stigma and Discrimination Interdisciplinary Research Workshop’ I attended in 2004, hosted by the Royal Tropical Institute of The Netherlands, also informed some of my thoughts about the research I conducted in 1998–99.

In the observations I made and in the narratives that emerged from the interviews I conducted with patients in various stages of treatment for Hansen’s disease, I found that several aspects of the outpatient treatment program were problematic for patients. Among the patients I interviewed, there was a high motivation to get well, but certain aspects of the medical encounter seemed to, from their perspective, confound their attempts to do so and create stigma where it had not previously existed. Iatrogenic stigma could be generated in the first encounter between health care workers and patients, at the moment of diagnosis (or before, if diagnosis is delayed), and at many points throughout the trajectory patients’ illness experiences. What follows is an attempt to give a few examples of how different types of relationships that are part of the biomedical encounter, including interactions between patients and health care professionals, the intersection of medication side effects and cultural expectations for appearance and the relationship between global health policy and the individual patient, may exacerbate or create stigma for people affected by Hansen’s disease in Brazil.

**Labeling**

Sartorius [6, p. 1470] notes that in mental illness, ‘[a] most obvious source of stigmatization is the careless use of diagnostic labels’. The moment
a patient first hears the biomedical term for what he or she has is an important one in terms of felt or enacted stigma. Being diagnosed with *lepra* (leprosy), a term that is full of metaphorical associations, can be quite devastating. In my observations in Rio de Janeiro, however, physicians and other health care professionals rarely used this term in talking to patients about their illness. Lobbying efforts on the part of physicians and the non-governmental organization Movement for the Reintegration of People Affected by Hansen’s Disease (MORHAN) have been successful in getting the terms ‘leprosy’ (*lepra*) and ‘leper’ (*leproso*) outlawed [19] in favor of *hanseníase* (Hansen’s disease), although the terms did not disappear from popular discourse. The idea behind this change was that it would reduce self-stigmatization and stigmatization of patients by others and would avoid confusion of leprosy with other diseases with which the word *lepra* was associated in Portuguese, such as dog mange, scabies and a variety of other common skin ailments. Although *lepra* is still a well-known term in Brazil, *hanseníase* is used almost exclusively in media reports and medical discourse about this disease today. However, *hanseníase* can also be problematic. Some patients I interviewed who knew that *hanseníase* and *lepra* were ‘the same thing’ felt that physicians used the term as a means of withholding information from them about their illness. For a few, *hanseníase* evoked a fearful response, as the term was quite unfamiliar sounding and almost a homonym for cancer in Portuguese (*câncer*), particular when it was called simply *hansen* as is common. Oliveira *et al.* [20] note that since its introduction, *hanseníase* has gradually come to be associated by many with the same, stigmatizing words and phrases often associated with *lepra* (e.g. ‘pieces fall off’, ‘incurable’, ‘fear’). For the most part, though, patients appreciated not having to use the word *lepra* to refer to their illness.

In my observations, the explanatory model about Hansen’s disease that is presented to patients by physicians, social workers or other health care professionals is as important as the terms that are used. The point that Hansen’s disease is curable is perhaps the most vital piece of information that patients need to hear up front, although the suggestion that patients will be cured (which is generally and logically interpreted as ‘problem-free’) as soon as they complete MDT can be misleading, as will be discussed further. I believe that it is important for early explanations to patients about their illness to incorporate the term *lepra*; though patients might not be aware of the connection between *hanseníase* and *lepra*, they might easily come across this piece of information when they leave the clinic and begin to talk with others about their illness. Knowledge that *hanseníase* ‘used to be called’ *lepra*, as some health care workers tell patients, might affect the decisions patients make about who they can talk with openly about their illness, which might thus protect patients from unnecessary stigma.

### Biomedical procedures

People diagnosed with Hansen’s disease may be subjected to a battery of medical tests and procedures before, during and after treatment with MDT. These range from relatively painless sensitivity tests that detect the numbness that is one of the primary diagnostic signs of the disease to surgical procedures (where available) to address nerve damage and other physical disabilities associated with advanced multibacillary Hansen’s disease. Two very common medical procedures performed in the clinics where I conducted observations seemed to generate stigma by creating visual markers of illness.

One such procedure, known as the *baciloscopia* in Portuguese and ‘skin smear’ in English, was a routine procedure at the facility where I spent most of my time. The skin smear involves the collection of tissue from lesions and from the colder areas of the body where Hansen’s disease bacilli are most likely to be concentrated. I observed tissue being collected from the tips of the earlobes, from the elbows and from the knees. In my observations of the procedure, a health care worker, usually a nurse, would make a small perforation in the skin with a scalpel, which was then used to gently scrape the area to collect a small amount of material to place on a slide, which was then ‘fixed’ by being...
passed quickly over a flame. The cells collected could then be viewed under a microscope. Skin smears are used to determine if a patient is paucibacillary (in which case few or no *M. leprae* bacilli may be present in the sample) or multibacillary (in which *M. leprae* bacilli will be visible). This can, in turn, determine the most appropriate treatment regimen. Skin smears can also be used to ‘diagnose multibacillary relapse in a patient who has already been treated’ [21, p. 2], and thus, it is an important medical procedure. With the skin smear, health care workers are not collecting blood but rather a sample of tissue or fluid (*linho* or lymph, I was told), although some bleeding may occur. Thus, cotton was usually placed over the scraped area with paper tape to hold it on. Nurses and patient joked about the ‘earrings’ (*brincos*) patients wore as they left the clinic and, in most cases, boarded a city bus. These bandages served as a sign of a physical problem. In the endemic area where the clinic I spent most of my time was located, there were thousands of individuals who had been affected by Hansen’s disease, either as patients themselves or as a family or friend of someone with the disease, and many who might be able to identify these bandages specifically as markers of Hansen’s disease. Since I conducted my research in 1998–99, standard procedures for skin smears have changed. According to a document produced by International Federation of Anti-Leprosy Associations [21, p. 2], skin smears should be taken ‘from two sites only: 1. One ear lobe 2. One lesion … If there is no suitable skin lesion, take the second smear from the other ear lobe, or from a site where active lesions were originally recorded or where a previous smear was positive’. This document, ‘How to do a skin smear examination for leprosy’, states that some clinics, such as the one where I observed multiple skin smears, ‘traditionally took smears from four or even six sites, but two sites are now considered adequate in most cases’ [21, p. 2]. The reduction in the number of skin smears taken is significant in terms of improving patient experience with this procedure, which in my observations was quite painful for many people to undergo (though skin scraping barely drew blood, patients winced strongly and were sometimes brought to tears during the procedure). Still, a single earlobe bandage may carry the same weight in terms of marking patients as potential carriers of Hansen’s disease. Health care workers might consider ways to minimize stigma for patients by providing less conspicuous bandages, for example, when practical.

Biopsies are another technique that produce physical markers of illness and are potentially stigmatizing. Like skin smears, biopsies are used to collect research data or to determine the type of Hansen’s disease a person has. Unlike skin smears, however, biopsies of the nerve taken from the hand or arm can produce permanent scars. A 50-year-old man I interviewed commented that one of the biopsies he had was very painful and complained, ‘I always leave here with more holes than a sieve’. A social worker I interviewed discussed her concerns with me about the number of biopsies she observed, and she felt that because this procedure was often performed as part of a training exercise for medical interns, they may ‘exaggerate’ in their collection of tissue, ‘so that everyone can see how it’s done or how it’s not done’. She said that she had seen cases in which people no longer wanted to be treated at the clinic where she worked after going through these diagnostic procedures.

At a different public health clinic, I observed physicians talking about taking a biopsy of a lesion on a young girl’s cheek. The social worker there protested that if it was not absolutely necessary, they should not do it because she would have that disfiguring scar forever. They decided to forego the biopsy. It was clear in her case that there were other options. It is important for health care professionals to weigh the consequences of performing a procedure that can have lasting effects on an individual’s appearance with the possible benefits of collecting a sample of tissue for analysis that does not necessarily contribute to that individual’s well-being and could cause a change in appearance that could result in lifelong stigma for that patient.

**Medication side effects**

Several medication side effects were unpleasant or physically damaging to patients but did not directly
generate stigma; indirectly, indigestion, fatigue, nervousness, memory loss, sleeplessness and impotency that were perceived as medication side effects by patients I interviewed created problems for patients in their relationships with people at work and at home and generated stigma in the sense of calling attention to the presence of a physical illness. In the few dozen cases that have been identified of children born with severe deformities associated with women taking thalidomide (prescribed for leprosy reaction) [22], stigma emerged for both children and families. Thalidomide use has since been restricted so that women of reproductive age are not allowed to receive the drug. (Still, in June 2006, I learned from representatives of MORHAN of two cases of infants that had recently born with possible thalidomide syndrome in Brazil. In one case, the mother had Hansen’s disease, and in the other, the mother received the drug from her husband, who was in treatment for Hansen’s disease.) The side effects of MDT and medications used in leprosy reaction that caused drastic appearance changes were those most commonly associated with stigma for patients I interviewed. In Rio de Janeiro, expectations of body shape and skin quality and tone were related to how these side effects were understood and experienced.

Both men and women I interviewed expressed distress about the uneven darkening in skin color that is commonly associated with the MDT drug clofazimine. Although transitory, these changes evoked unwanted comments from members of patients’ communities. Heijnders [3, p. 445] also notes that this side effect was perceived as a ‘trigger’ to ‘exposure and discrimination’ in Nepal. Among the patients I interviewed, several expressed their dismay as being perceived as ‘black’ or ‘darker’ (mais moreno), suggesting a concern with a change in racial categorization in a country where skin color and class association are often linked. One woman, 44 years old at the time of the interview, said she had some problems because of her change in skin color, which resulted from taking clofazimine for 2 years. She said, ‘I experienced stigma because it messes with your color. I was black—I changed color, right? I had been pale, right?’ People in her neighborhood began to ask, ‘Why are you black like that? What is that?’ A man, 55 years old, experienced a similar reaction in his community. Friends would say to him, ‘You’re turning black. What’s that?’ I’m taking the medicines and this is what’s happening … Everyone was worried because of this medicine …

The changes in the body that resulted from the steroid prednisone were also quite difficult for many patients to cope with. Those who had to take this drug off and on for several years as they experienced different episodes of leprosy reaction were most affected. Facial swelling and weight gain were the most visible examples of physical changes that resulted from prednisone. These side effects, which resulted in drastic appearance changes, caused self-esteem loss and self-stigmatization that translated, in some cases, to self-imposed isolation and a reduction in social activities, particularly for younger women, because of cultural ideals that link femininity, youth and slenderness in Brazilian society and because women were prescribed prednisone more frequently than men, who could take thalidomide. A physician I interviewed in Brazil expressed frustration at not being able to prescribe thalidomide to women because so many women suffer from taking prednisone for extensive periods of time. Thalidomide is arguably a much better drug for leprosy reaction, he said, and he felt that exceptions should be made for women who had a particularly difficult time with leprosy reaction and who could be given detailed instructions on how to prevent pregnancy. One young woman I interviewed, then 22, summarized how changes from both clofazimine and prednisone affected her daily life:

I was very dark, and I gained a lot of weight … So I changed a lot. People would say, ‘Girl, is that you?’ … My body changed a lot. So … my
wardrobe, all my pretty clothes are put away. They don’t fit me. So I gave my bikini away because I had to buy a larger one for me … I stopped going to the beach.

While such lifestyle changes may seem superficial, they have the potential to alter one’s life and socialization patterns dramatically. Appearance changes associated with Hansen’s disease treatment contributed to this young woman’s avoidance of socializing altogether, beyond her immediate family.

It might be argued that iatrogenic stigma emerging from medication side effects is unavoidable, since these medications are crucial to the control of the disease and to the prevention of severe disabilities. While the side effects of the drugs may be inevitable (barring future pharmaceutical research efforts to create leprosy medications with fewer side effects), stigma can be mitigated if patients are well prepared in terms of what to expect. The WHO [12] recommends that patients be made aware of potential side effects when medications are administered. Although some physicians are wary of inducing a somatic response in patients through suggestion, if patients are aware of possible side effects that affect, for example, their appearance, and if they know that these changes are ultimately reversible, stigma might be circumvented.

**Disability as a function of late detection and leprosy reaction**

In a segment for a documentary [23] for which I assisted the producer in finding interview participants, I conducted an interview with a physician and epidemiologist about some of the misconceptions people had Hansen’s disease. He stated:

The great fear that people have, truthfully, is associated with disability, of becoming crippled. *Hanseniasis* has the stigma of leaving people crippled. We call attention to the fact—we who work in research, who work with the disease—that *hanseniasis* does not disable people. What disables people is poor medical care that people receive via the public health networks.

In other words, with the current treatment that is available for Hansen’s disease, no one should be suffering from Hansen’s disease-related disabilities. Complications and disabilities associated with Hansen’s disease are largely a function of delays in detection of the disease [24]. Late detection is in part due to patient delay in treatment seeking, as the early symptoms of Hansen’s disease are often quite mild and easy to ignore. However, many of the patients I interviewed (40%) had received multiple misdiagnoses of their conditions from physicians at various public health posts, and, in some cases, at private clinics, before finding out they had Hansen’s disease. Patients were misdiagnosed repeatedly as having a variety of skin conditions or other more serious problems such as diabetes, rheumatoid arthritis or syphilis. Some were prescribed antibiotics that may have complicated their symptoms of Hansen’s disease.

According to the Municipal Ministry of Health of Rio de Janeiro [25], there are several situations in which the medical community loses the opportunity for a diagnosis. Patients may go to a clinic where their symptoms are not given priority or where health care workers do not schedule them for a return visit; the health post staff may not recognize Hansen’s disease or they may not have the diagnostic tools to test for it; patients may be misdiagnosed and treated for another illness; patients may not have access to or know where they can find treatment and patients may go in for treatment of another problem but have symptoms of Hansen’s disease (that the patient has not been concerned with) that go undetected by the medical staff. Failure to identify Hansen’s disease is sometimes the result of preconceived ideas about symptoms held by medical personnel who are not trained in Hansen’s disease diagnosis. Health care workers may expect Hansen’s disease symptoms to resemble images of advanced, untreated cases of the disease. Instead, the most common early diagnostic sign of Hansen’s disease is a depigmented skin patch that is lacking in feeling.

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or sensitivity. Hansen’s disease is a complicated disease that manifests itself in different ways according to each person’s individual immune system, which can, arguably, make diagnosis difficult even for those who have had specific training, but physicians in endemic areas should always consider Hansen’s disease as a possibility when seeing patients.

Miscommunication between health care professionals and patients regarding leprosy reaction also contributes to the development of visible symptoms, disabilities and the perception (by patients) that they still have Hansen’s disease. The emphasis on Hansen’s disease curability with MDT can be frustrating to patients who continue to have problems. Also, because patients are declared *alta* (a Portuguese term for being medically ‘discharged’) when MDT is complete, patients may be less likely to be compliant with follow-up visits. Yet leprosy reaction can cause progressive nerve damage in people who do not seek further treatment. One of the most severe Hansen’s disease-related problems I saw in Brazil was in an elderly woman who had completed MDT. Though cured, she had incurred permanent nerve damage and continued to experience problems with leprosy reaction. Her neighbor brought her into the health post; when a physician I was working with called me to observe her case, I noticed that most of the patients in the waiting room, who were there for a variety of problems, were looking on with some trepidation or had moved away from where she was sitting (on top of a rolling cart that was not quite a wheelchair). The skin on one of her legs had turned black from necrosis, and she suffered from significant bone resorption in her fingers and toes. Though compliant with her MDT treatment in previous years, she did not apparently seek medical treatment as her nerve damage got progressively worse due to leprosy reaction. Patients’ resources and life circumstances are important in terms of compliance with treatment and medical visits (particularly after MDT is complete) that may prevent disability. However, health care workers also play a role in terms of conveying messages to patients about the possible long-term follow-up care that may be required for some individuals with Hansen’s disease. The construction of Hansen’s disease as easily curable with MDT and of leprosy reaction as something separate from the disease itself comes from policy that is made at national and international levels, by the Brazilian Ministry of Health, the Pan American Health Organization and the WHO. While it might be argued that being able to say that Hansen’s disease is curable in 6 months to a year of MDT reduces stigma, the benefits of this conceptual model might be outweighed by the potentially stigmatizing physical problems that arise because of patient misunderstanding of the importance of follow-up care in those who experience leprosy reaction after MDT is complete.

### Treatment location

As noted above, treatment centers that are specifically oriented toward the treatment of one particular health-related condition accrue stigmatizing associations. The leprosarium, the tuberculosis sanatorium and the mental hospital are all classic examples. As MDT began to be used widely in Brazil, the Ministry of Health began to decentralize Hansen’s disease treatment services, moving away from a vertical system that involved the treatment of the disease at specialized centers. In 2001, a law was passed that made Hansen’s disease a *basic health service*, with the idea that eventually staff at all general public health facilities in Brazil would be trained in Hansen’s disease diagnosis and would have MDT treatment available [26, p. 1574].

When I conducted research in Brazil, Hansen’s disease was treated at a small number of referral centers around the greater Rio de Janeiro metropolitan area, and on my most recent visit to Brazil in 2006, decentralization of Hansen’s disease treatment was not yet complete. Still, most of the referral centers I visited did not seem to be ‘known’ places for Hansen’s disease treatment and the visits that patients made to these locations did not seem to generate added stigma. However, one treatment center I visited was on the grounds of a former *hospital-colônia*, a community that, throughout much of the 20th century, served as a confinement
center for people diagnosed with Hansen’s disease. There are 33 of these communities in Brazil today [27]. These locations already have some of the tools in place for the treatment and prevention of disabilities, and in many cases, there is also a resident population of individuals who are now cured of Hansen’s disease but continue to make the grounds of these facilities their home. In this sense, because these individuals sometimes require the care of physicians who are specialized in disabilities associated with Hansen’s disease, it is practical to also have these facilities made available for outpatient treatment.

The treatment center I visited that was also a former leprosarium offered treatment both for Hansen’s disease and for dermatological conditions. Six of the educational meetings I attended were at this clinic. These were held in the large waiting room that served patients with several different conditions. These meetings revolved around the theme of Hansen’s disease and popular beliefs that people had both about the disease and the facility, as the staff was aware that the name of the facility had long been associated with Hansen’s Disease and forced confinement. At one meeting, the social worker began the discussion by saying, ‘Have you all heard this is a horrible place?’ Two women spoke up and said they had friends who had advised them not to go there. ‘Why?’, asked the social worker. One woman responded that it must be because of lepra (leprosy). ‘Do you know anything about it?’ The same woman said, ‘no. I’ve heard of it [though]’. Another woman, there with her child, asked, ‘Is there a risk of catching it?’ And thus began what I saw as a very productive conversation that had the potential to greatly to prevent self-stigmatization of patients who were there for Hansen’s disease treatment and to mitigate the stigma associated with the facility itself. The social worker pointed out, ‘If you get hanseníase, it’s probably not from here at [this facility]. Everyone here is in treatment. You might [more likely] get it on the bus, or outside of here.’

If former leprosaria are to be used as outpatient treatment centers for Hansen’s disease, education about Hansen’s disease must take place not only within the treatment center but also in the surrounding community. Psychologist Suzana Duran [28] has described the case of a woman diagnosed with Hansen’s disease who met a resident and former patient while hospitalized on the grounds of a former colônia. He convinced her that her identity would be forever that of a leper (leprosa), which had perhaps been his experience in an earlier era of Hansen’s disease control. She moved onto the grounds of the facility (though this was not sanctioned or known about by the facility officials), and when her young son also exhibited symptoms of Hansen’s disease, she did not assure that he was compliant with the treatment program, as she had been convinced of Hansen’s disease’s incurability (Barrett [29] notes that one of the primary ways in which leprosy stigma in India is perpetuated is through the cycle of patients not believing it is curable, hiding or not seeking treatment and then developing the archetypal deformities and disabilities associated with leprosy). He began to experience stigma from teachers, parents and fellow classmates at his school as he was not only known to live on the grounds of a facility associated with Hansen’s Disease but also exhibited visible signs that something was wrong. Educational sessions conducted by staff of the colônia seemed to make a difference in how the boy was subsequently treated in school. In the monograph Duran wrote describing this case and in an interview I conducted with her, she illustrated a successful intervention in which a team of health care professionals worked together to find a way to reverse some of the effects of the self-stigmatization of this woman and the discrimination toward her son.

With the increased availability of MDT at general health posts in Brazil, the location of Hansen’s disease treatment may become less stigmatizing. On the other hand, in a setting where people are being treated for multiple disorders, there is a risk that Hansen’s disease patients may perceive and experience greater stigma from other patients than they would in a health post where everyone is being treated for the same condition (Artur Custódio de Sousa, personal communication). In general, the benefits of decentralization in terms of increasing
access to treatment might outweigh the possible drawbacks.

**Resgate: ‘rescuing’ patients who have abandoned treatment**

On two occasions during my 1998–99 research in Brazil, I was able to accompany a social worker on ‘house visits’, or visits in search of patients who had abandoned treatment. Ideally, all health posts are supposed to follow up on patients in this manner, but due to lack of resources, many clinics did not have the personnel (social worker or psychologist) who could make these visits. House visits also require a great deal of time and expense, and most health posts did not offer a form of transportation for their representatives. The social worker I accompanied had access to an ambulance to make these visits. We were unsuccessful in terms of finding patients, and I felt that the visits, as they were structured, were invasive and capable of generating stigma for the patients we were seeking. Arriving in an ambulance may have alerted family members or neighbors that the person we were looking for had a health-related issue. At one house where no one answered the door, the social worker rang the siren on the ambulance to try to bring people out; only neighbors emerged, thus calling attention to the household of the patient. While the social worker was discreet about not mentioning the word *hanseníase*, she left contact information with relatives of patients (who may or may not have known about the person’s illness); this information could have identified patients as having Hansen’s disease or at least having a health problem that was serious enough for health ‘officials’ to come looking for them. House visits can be a valuable part of Hansen’s disease control and can be constructed differently so as to minimize potential stigma for patients and their families. One promising means of ensuring adherence to treatment has been made possible by the expansion throughout Brazil of a program known as the Programa Saúde da Família (PSF), or Family Health Program. Through this program, health agents make frequent house visits and involve entire families in working toward the health maintenance or treatment of its members [30]. If the family is working together on health issues and if PSF representatives are understood as promoters of general health by the community, the potential for stigma associated with house visits is greatly reduced or eliminated.

**Stigma and the biomedical gaze**

Patients I interviewed also described stigmagenerating aspects of the clinical experience that are not specific to Brazil and not specific to Hansen’s disease treatment. Exposure to the clinical gaze, particularly for the purposes of medical instruction or research, was distressing for some of the patients I interviewed. I observed and sometimes became a party to the objectification of patients who were asked to stand, sometimes unclothed or partially clothed, for an audience of several medical interns. Despite the common occurrence of this form of instruction or demonstration of patients’ cases, the referral centers where I spent most of my time, were highly praised by patients as locations where they felt that they were treated as ‘human beings’ by the doctors, nurses, and staff. With the exception of interns who passed through these clinics, the physicians and staff at the Hansen’s disease clinics I observed had dedicated their careers to the treatment of this illness and tended to be sensitive to the needs and backgrounds of patients. However, in their interviews, patients also described other health posts they had visited to provide a contrast in terms of the amount (or lack) of care and sensitivity they had received at these places. Where they occur, disparaging attitudes and treatment toward patients in public health facilities by health care professionals in Brazil are functions of strong cultural, socio-economic and even linguistic (in terms of dialect) differences between physicians in particular and those who depend on public health facilities. Physicians may already hold *preconceitos* (preconceptions, often used as a synonym for stigma in Brazil) about patients who come from low-income or shantytown (*favela*) communities, and this may
(and often does) extend to how patients are treated in the clinical encounter and how they are made to feel about their illness.

**Discussion**

The above observations on the ways in which the medical encounter generates or perpetuates stigma are not meant as a condemnation of physicians and other health care workers. Most of the issues discussed are not solely in the hands of individuals who work in public health posts or clinics in Brazil or in other nations where Hansen’s disease is a public health problem. Treatment policy for Hansen’s disease is formulated at the international level. National and municipal allocation of resources for public health services and salaries and extreme social stratification in Brazil are other external factors that affect how the biomedical encounter for patients might play out.

What, then, can or should we do about stigma that is a by-product of the medical encounter? Weiss and Ramakrishna \[31, online\] have suggested:

> It is important to note that efforts to distinguish stigmatizing behavior from appropriate precautions for some health problems may require a delicate balance of public health risks and restrictive or exclusionary management based on medical and epidemiological evidence. Though exclusionary, such behavior is different from what we mean by stigma as the term is understood in the context of public health.

I would argue that stigma is still present and a matter of concern, even when it is generated in the context of what is deemed a necessary public health measure for the protection of patients or the wider society. ‘Appropriate precautions’ are relative, since public health policies and biomedical understandings of what is appropriate or necessary change over time. At one time, public health officials around the world viewed forced isolation of Hansen’s disease patients to be an appropriate precaution, though it was highly stigmatizing for patients. In hindsight, we can question the supposedly science-based necessity of isolation, and we can analyze how policy decisions about Hansen’s disease throughout the 20th century were influenced by politics and colonialism, but few questioned the appropriateness of the isolation policies at the time. Perhaps all forms of medical interventions or public health policies that create negative self-perceptions or social disadvantage or exclusion for the individual should be considered ‘stigma’, though stigma may be seen as unavoidable, or in some cases, positive, within a public health framework. Physical exclusion of people affected by Hansen’s disease is no longer a biomedical policy or a necessity. However, the contemporary outpatient treatment program for Hansen’s disease, which is unquestionably necessary to both prevent severe disability in patients and decrease the incidence of the disease, also has the potential to generate increased stigma and problems for patients. Because of the relative standardization by the WHO of Hansen’s disease treatment worldwide, the data presented here could be applied in a general sense to other parts of Brazil and elsewhere, although individual cultural and regional differences will determine whether or not certain aspects of the medical encounter will result in stigma. For example, side effects of MDT (or any form of treatment with significant side effects) should always be considered as a ‘possible’ source of iatrogenic stigma; however, weight gain caused by prednisone may be more traumatic and stigmatizing in the city of Rio de Janeiro, Brazil, than they would be in a region or nation where being thin is not as significant to self-esteem. The potential of stigma arising from the medical encounter is intimately connected not only to pre-existing stigma specifically related to Hansen’s disease but also to local religious beliefs, politics, gender roles, race and class stratification, employment patterns and cultural constructions of the health and the body. It is hoped that by providing some of the examples given in this paper of how iatrogenic stigma in Hansen’s Disease might arise or might be circumvented, those who work daily with people affected by this and other diseases around the world will be compelled to
further consider the complexity of their role in patients’ experiences of illness.

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Conflict of interest statement

None declared.

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