Sociocultural considerations in the treatment of leprosy in Rio de Janeiro, Brazil

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Introduction

Although a cure for leprosy was found in the 1950s, and an improved treatment regimen was developed in the 1980s, there were still 43,933 newly detected cases of leprosy in Brazil in 1998 (when the research presented here was begun), and the number of new cases detected in Brazil each year has remained steady at around 45,000.¹ Brazil, with a total of 72,953 cases, is second to India for the highest number of cases of leprosy in the world.²³ Leprosy has been a problem in Brazil since its introduction by Europeans in the sixteenth century. The disease was endemic to many of the European nations that sought to colonize Brazil, including Portugal, Spain, France, and Holland. In addition, many slaves were brought from areas of West Africa where leprosy was endemic.⁴ Internal migration throughout Brazilian history and the development of shantytowns (favelas) in Brazil’s major cities contributed to the transmission of leprosy. Today, large percentages of urban residents (over a third of Rio de Janeiro’s population, for example) live in shantytowns called favelas. The living conditions in the favelas are substandard; the presence of other diseases, contaminated water supplies, and poor sanitation in the favelas may lower immunity among residents, and the fact that small, poorly ventilated homes are shared by large families may contribute to the transmission of leprosy. However, leprosy is also endemic in the Amazon region, where living conditions are very different from those in the cities. In more remote areas of Brazil, lack of access to medical services, coupled with historical and genetic factors, may be responsible for high prevalence rates. Cultural practices and local perceptions of leprosy, many of which will be discussed in this article, also affect detection rates, patient adherence to treatment, and the ways in which patients experience disease.

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Research objectives and methods

Leprosy can greatly alter people’s lives either temporarily or permanently. It is important to understand how patients experience leprosy in order to identify some of the problems with leprosy diagnosis, treatment, and cure. For 11 months in 1998–1999, I conducted research on cultural aspects of leprosy in Rio de Janeiro, Brazil, with a grant from the Fulbright Organization. The primary goals of this research were to understand patient perspectives on the experience of leprosy in every stage of the illness and to determine how this information can be utilized not only to improve the quality of life of patients but also to reduce incidence and prevalence rates of the disease in Brazil.

The first objective required identification of problems patients experienced in different stages of the disease. It was also important to identify how elements of Brazilian culture influence patient experience and shape popular knowledge and belief about leprosy. Patients’ experiences of the disease in general and with the multidrug therapy (MDT) treatment programme for leprosy were elicited from formal and informal interviews and conversations with leprosy patients. Also, through observations of interactions between patients and healthcare workers at different health posts in Rio de Janeiro, an assessment was made of the roles of the Brazilian healthcare system in helping the patients make sense of leprosy and MDT. The data collected could be applied to the other objectives of this study of improving patient quality of life and lowering incidence and prevalence through 1) providing ideas for new approaches to leprosy education in the media in order to reduce stigma and promote early detection of symptoms, 2) suggesting ways the treatment program could potentially be improved, and 3) finding ways to improve communication between healthcare workers and patients in all stages of leprosy treatment.

My primary methodology for this project, the collection of patient narratives (or ‘illness narratives’) about leprosy and leprosy treatment, is one that could also be used by healthcare workers in order to improve communication and understand more about the subjective experience of illness. Arthur Kleinman,5 an anthropologist and psychiatrist who coined the term ‘illness narratives,’ noted the importance of listening to patients and understanding their words in the context of the particular culture or subculture of which they are a part. Using a structured set of interview questions as a guideline, I collected illness narratives of 43 patients (24 women, 19 men), 40 who had begun or had completed MDT and three who had recently been diagnosed or were waiting for skin smear results. The illness narratives I collected from patients were short life histories, with a focus on the time period beginning with the first appearance of leprosy symptoms. I asked questions regarding every aspect of the disease process as well as questions about patients’ background, religion, domestic situation, social activities, employment, and neighborhood.

In addition to illness narrative interviews, I also observed interactions between healthcare workers and leprosy patients. I accompanied several patients (144 total) through clinic visits and asked them informal questions about their experiences. I conducted structured interviews with physicians, nurses, psychologists, social workers, government officials, and volunteers who work with leprosy. I worked with volunteers of the non-governmental organization, MORHAN (Movement for the Reintegration of Hansen’s Disease patients), accompanying them when they presented educational programs about leprosy. I attended self-help groups and educational meetings for leprosy patients held at two public health posts. I also attempted to understand popular conceptions of leprosy in Brazil through media analysis and through discussions with several groups of parents at a favela (shantytown) school. All interviews and
conversations were conducted in Portuguese. All structured interviews, with patients and with healthcare workers, were tape-recorded.

Sample population

Most of the patients I interviewed or met in Rio de Janeiro came from working class neighbourhoods or favelas in the industrial Zona Norte (North Zone) of Rio de Janeiro or in the Baixada Fluminense, a lowland floodplain area on the outskirts of the city. The Baixada Fluminense has one of the highest concentrations of leprosy patients in the world, with prevalence rates of leprosy of up to 8.8 per 10,000 in its municipalities in 2000.6 In formal interviews, I asked patients several questions about their neighbourhoods and the issues of concern in their community. The number one issue, mentioned by 21 patients (49% of 43 interviewees), was violence, characterized mainly by gun battles between drug traffickers and police. Several patients mentioned the lack of public sanitation and the problem of open sewers in their communities as a primary concern. Other concerns mentioned included flooding, unemployment, health and disease, lack of transportation services, lack of running water, unpaved roads, malnutrition, rats, mosquitoes, and, as one patient said, ‘the economic future of Brazil.’

In the sample of 43 patients with whom I conducted formal interviews, 10 of 19 men were working or had worked in manual labour such as in construction, metallurgy, or stonecutting. Other occupations held by men I interviewed included door-to-door salesman, artisan, student, and soldier (in the army). Of the 24 women I interviewed, nine worked or had once worked as either domestic servants or cleaning women. Other common occupations for women in the sample were student, cashier, housewife, and factory worker. Patients ranged in age from 13 to 70, but most patients I interviewed (86%) were between the ages of 20 and 50 years. The health post where I conducted my structured interviews was a referral center for patients with leprosy reaction, so the problems of leprosy reaction were featured perhaps more prominently than in an average sample of leprosy patients. In my sample of 43 patients, 74% were being treated or had been treated for leprosy reaction at some point.

Folk and patient models of leprosy in Brazil

Folk models are culturally constructed models of thought about some aspect of the world. In the course of my research, I learned quickly that there are some commonly held folk beliefs about leprosy in Brazil but that people are very flexible and open to new information and new experiences. These folk models, many of which I found to be held by Brazilians of different socioeconomic classes, are presented in Table 1.

CONTAGION

The models that patients construct about different aspects of leprosy incorporate elements of the folk and biomedical models of the disease in addition to elements from their own experiences of the disease and the experiences of other patients they meet at the health post. Several patients I interviewed believed they acquired leprosy from other people. However, casual contact was often cited; some patients thought they got leprosy from having touched
Table 1. Biomedical versus folk models of leprosy in Brazil

<table>
<thead>
<tr>
<th>Biomedical model promoted of ‘<strong>hanseníase</strong>’ or ‘<strong>lepra</strong>’ in Brazil</th>
<th>Folk and patient models of ‘<strong>lepra</strong>’ in Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Contagion and causality</strong></td>
<td></td>
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<tr>
<td>Passed through respiration, through prolonged and intimate contact with a person who has the contagious form of the disease who is not in treatment</td>
<td>Comes from: contact with dogs, rats, the forest, the ocean, or contaminated water; casual contact with a sick person or his or her clothes or personal items; having sexual relations; having bad blood; eating certain foods; sorcery, evil eye, or a test/curse from God</td>
</tr>
<tr>
<td><strong>2. Symptoms</strong></td>
<td></td>
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<tr>
<td>Spots on the skin that do not itch, do not hurt; insensitivity in the spots and in extremities; tingling in hands and feet</td>
<td>Skin lesions and spots that itch; itchiness all over the body (not just in areas with lesions)</td>
</tr>
<tr>
<td><strong>3. Development of disease</strong></td>
<td></td>
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<tr>
<td>If untreated, insensitivity can lead to wounds and subsequent infection and occasional amputation; nerve damage can lead to disability</td>
<td>Rotting of the flesh; limbs, fingers, and toes fall off; death</td>
</tr>
<tr>
<td><strong>4. Cure</strong></td>
<td></td>
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<tr>
<td>Treatment plan of 6 months to 2 years results in cure; all bacilli are killed; follow-up to prevent disability</td>
<td>Incurable or curable through religious faith or alternative treatments</td>
</tr>
</tbody>
</table>

someone once who may have had leprosy, from having visited a hospital or former leprosarium, or from a sexual encounter.

Many of the patient beliefs about contagion are related to elements of the physical environment in low-income neighbourhoods or **favelas**. Because healthcare workers often tell patients that their living conditions are responsible for their disease (which may be accurate in the more abstract sense of lowering immunity), patients come to believe they can acquire leprosy directly from their environment. One young woman associated her disease with time spent playing in a polluted river when she was younger:

‘I don’t think anyone in my family had it. But where I lived . . . the river is very filthy, right? So, I used to go into the river to retrieve a ball. I was a kid, 12, 13 years old, and shortly after I came down with this disease. Because he [a doctor] said that it comes from dirt (**sujeira**) and then from the family.’ Another woman thought she got leprosy from the open ditch (**valão**) near her house, which was often full of garbage and raw sewage. ‘I lived breathing that air from the ditch every day . . . It’s possible that this disease could be in a ditch, right?’

One of the most common beliefs in Rio de Janeiro and throughout Brazil is that leprosy comes from dogs. There are many possible explanations for this folk belief. **Lepra** (leprosy) is a synonym for **sarna** (dog mange) in Brazilian Portuguese. Volunteers at MORHAN suggested since many of the half-wild dogs that roam the streets have open sores, people think they have leprosy. Dogs may also be associated with leprosy because they are depicted in representations of the patron saints of skin diseases, St Lazarus and St Roch. Dogs are also considered unclean animals in Muslim societies, and there is a history of Islamic influence in both Portugal and West Africa, regions from which much of Brazilian culture derives. A few patients I interviewed speculated on the common folk model about dogs, but other animals, such as cats and rats, were also implicated.

Another belief that exists in Brazil is that leprosy can be contracted through eating fish or
pork. The belief that leprosy comes from eating certain foods is common in many parts of the world. In educational meetings with patients, several patients asked the social worker if it was possible to contract leprosy through eating pork. One patient I interviewed speculated that he may have acquired leprosy from eating fish. He said he had eaten fish he caught from a swamp; no one else in his family would eat them, so he ate them all himself. Since he was the only one to eat the fish (and to get leprosy), he concluded this was the source.

A folk model of contagion in Brazil that has been reported in the literature is that leprosy derives from ‘burned blood.’ In Northern Brazil especially, it is believed that ‘blood is ‘burned’ after a person drinks hard liquor and takes certain medicines—‘burned blood’ (sangue queimado) is a synonym of skin disease, and this is a synonym of MH (Morus Hansen). A patient I interviewed told me that he overheard a relative telling someone he (the patient) had ‘bad blood’ (sangue ruim) because of leprosy or perhaps as a description of his condition.

Evangelical or Pentecostal religions have become very popular in Brazil, which was once a predominantly Catholic country. About half of the patients I interviewed (20 of 40 patients whose religion I recorded) were members of an Evangelical Church. The position of the Evangelical Protestant churches in Brazil is that certain illnesses are punishments from God. Most of the Evangelical patients I interviewed, however, said that they saw leprosy as more of a life lesson than a punishment. Through having leprosy, they felt they were given the opportunity to learn about suffering and compassion. Afro-Brazilian religions look at illness as the result either of sorcery (feitiço) by a human against another human or of having offended a particular supernatural being.

SYMPTOMS

Popular models of what leprosy is ‘supposed to look like’ represent an important problem in both self-identification of leprosy and physician diagnosis. As noted in Table 1, the popular model is that leprosy causes itchy patches of skin, suppurating lesions, rotting flesh, and loss of limbs. Because the initial symptoms of leprosy are often a painless area of depigmented skin, patients often ignore early warning signs. In addition, skin problems (e.g. vitiligo, fungus, eczema) are very common in Brazil, so that early leprosy symptoms are generally not a cause for alarm and are not recognized by patients.

Patients I interviewed found that once they did identify problematic symptoms in themselves, they could not immediately get a diagnosis from physicians. Late detection seems to be a significant problem in Brazil. Queiroz and Puntel note that close to 90% of the 33 leprosy patients they interviewed in Campinas, São Paulo had been misdiagnosed at least once before finding out what they had. In Claro’s study of 45 leprosy patients in Rio de Janeiro, 12 (28%) had experienced misdiagnosis of their disease, and two others (5%) were told they had nothing wrong with them. Popular models of leprosy affect physicians’ ability to diagnosis leprosy in its early stages. According to a physician and epidemiologist I worked with, many doctors in Brazil ‘think that a patient has leprosy only when he is completely deformed.’

Many patients I interviewed had stories of their long road to finding a diagnosis. Of the 43 patients I interviewed, 18 (41%) had received a misdiagnosis of their condition. Patients’ leprosy symptoms had been misdiagnosed as one or more of several different conditions, including fungus, allergy or rash, arthritis and other joint inflammation problems, diabetes, syphilis, and circulation or heart problems. Some patients had been treated for other
conditions, with negative results. Patients had been misdiagnosed expressed extreme frustration and emotional stress in their quest to discover what wrong with them.

While educational campaigns can help in terms of patient self-detection, physicians must have better training in identifying the initial symptoms of leprosy. A public health official told me that several spots for medical students to receive training in leprosy diagnosis had been made available in Rio de Janeiro, but few students chose to receive this training. There is very little financial incentive for physicians to learn more about leprosy when it is treated at public health posts, where physicians are paid very low wages for their services.

TREATMENT

Only four of the patients I interviewed formally had sought alternative forms of treatment for leprosy prior to or during treatment, but I also investigated what alternative forms of treatment were available for patients. Religious cures for diseases with a particularly complex aetiology are commonly sought by Brazilians. In the Afro-Brazilian religion Candomblé, for example, Omolu is the orixá (god) who is responsible for both causing and curing skin diseases. A ceremony or offering to Omolu, or to his correspondent Catholic saints St Lazarus or St Roch, might be made in seeking treatment for leprosy. Faith healing is an important element of the Evangelical churches, and some patients mentioned that they had been encouraged to abandon treatment for leprosy in favour of prayer.

Herbal remedies are another available alternative treatment for leprosy. I purchased several leaves and bark samples that street vendors in open markets in Rio de Janeiro told me were useful for lepra (leprosy). Most of the plants, the vendors told me, were to be prepared as a tea or placed in bathwater. The plants I collected include urucum (annatto, or Bixa orellana), aroeira (Schinthus terebinthifolius), erva de Sáo João (St John’s Wort or Hypericum perforatum), erva de Santa Maria (possibly Solanum americanum), espinheira santa (possibly Maytenus aquifolium), and amor do campo (possibly Melhonia trifoliata). Brazilian scientists were studying the properties of urucum for treating leprosy earlier in the twentieth century. One of the leprosy patients interviewed by Claro in Rio de Janeiro said that she used aroeira to make a bath. The patient told her, ‘There’s no better remedy for these inflammations than aroeira. My legs were one wound that just opened up. I got better with this herb. It was the medications and the aroeira.’ Some of these plants seem to have properties that might alleviate symptoms of leprosy and leprosy reaction, if research can show that no negative drug interactions would take place if used in conjunction with MDT.

Problems in the experience of treatment

SIDE EFFECTS

Of the 40 patients who were taking or had completed MDT, 29 (73%) suffered side effects of the medications. The changes in skin tone caused by clofazimine were reported by women in particular, who were concerned with their appearance. In Brazil, body image (emphasizing physical beauty and thinness) is extremely important for both men and women, and changes in appearance due to medication side effects changed the way some patients interacted with others and how they dressed in public.

In general, treatment for leprosy reaction was more problematic than MDT, in terms of side effects. Appearance changes resulting from prednisone were a significant problem,
especially for women, who were distressed about weight gain and facial swelling. Physiological dependency also seemed to be a problem with prednisone. Patients were usually given 70 mg of prednisone per day to begin, and this dose was lowered by 10 mg each week. A common complaint of patients was that as soon as they reached the lower doses of the medication, they would have a recurrence of fever, pain, and lesions. Women in Brazil are limited to prednisone as a treatment for erythema nodosum leprosum, since the alternative, thalidomide, causes severe birth defects. Several dozen (documented) babies with severe birth defects were born in Brazil to mothers who received thalidomide for leprosy treatment before it was outlawed for women of childbearing age. Pentoxifylline is available at a few health posts, but this more costly drug was not yet in widespread use at the time of my research.

ABANDONMENT OF TREATMENT

Because of the fact that most of the patients I met were present in the clinic (as opposed to having abandoned treatment), I was not able to collect much data from these interviews about reasons for abandonment. I did, however, learn some reasons for abandonment from interviews with healthcare workers and MORHAN volunteers. According to one volunteer, patient misunderstanding of medication side effects is the most common problem. When physicians do not explain that the medications can have side effects, patients may think that the treatment is worse than the disease itself, and they might see no reason for continuing with treatment.

In a study of leprosy patients in Rio de Janeiro, Claro found that patients’ reasons for temporary abandonment of treatment or missed appointments included: ‘the occurrence of strikes among health professionals, taking trips, denial of the illness, the occurrence of reactional episodes, undesirable effects of the medicine, and lack of information about clinical aspects of the disease.’ In her study of how leprosy affects men and women in Ribeirão Preto, São Paulo, Oliveira found that men and women have different reasons for abandoning treatment or for irregular attendance at the health post. Using a structured questionnaire with 202 leprosy patients (132 men and 70 women), she found that, ‘[f]orgotten appointments, undesirable side-effects, fear of medication, preference for alcoholic beverages, loss of work, and disbelief in the diagnosis were the reasons men gave for their absences. Women mentioned adverse reactions to treatment as the main impediment, followed by forgetfulness.’ Alcoholic beverages are not supposed to be consumed during treatment because they make the MDT medications less effective and because both alcohol and the medications affect the liver. This is an issue for men in particular, since drinking beer and cachaca (cane liquor) constitute an important part of masculinity and socialization for men.

Several of the above problems were listed as issues for patients I interviewed but not as causes for abandonment of treatment. Of the 40 patients I interviewed who had begun or completed treatment, eight patients (20% of those in treatment) had missed an appointment or missed a few days of medicine at some point. Irregular attendance is not the same as complete abandonment of treatment, but it can have negative effects on patients’ treatment programmes. These patients missed appointments for reasons related to work, family problems, other illnesses, and inability to pay for transportation to a health post. Some health posts provide transportation tickets for patients, but most cannot afford to do this consistently. Only one patient I interviewed had abandoned for an extended period of time; he had spent several
months in another city. During the many months of MDT, patients may move to a different city or state, either temporarily or permanently, for work or other reasons. While it is ideal for one physician or clinic to monitor a patient’s progress, it would be practical for patients if they could pick up medications while on the road.

**Patient perception of being ‘cured’**

Patients who had completed MDT but continued to experience problems with leprosy reaction said that they were confused because they had been declared ‘cured’ by a physician. For patients, being ‘cured’ means that they are healthy. Since many patients have reaction-related problems for years after MDT is complete, they think they still have leprosy and are frustrated when physicians tell them they do not. Also, patients who are unable to work because of leprosy reactions have a hard time receiving disability pensions from the governments if they have completed MDT. Perhaps a restructuring of the terminology used to refer to the completion of treatment would help patients to better understand the disease process and to have an easier time in acquiring disability benefits.

**A note on terminology**

In medical discourse and media campaigns in Brazil, the word *hanseníase* (Hansen’s Disease) is increasingly being used in place of leprosy. Use of the word *lepra* is discouraged by law and is not used in the literature of non-governmental organizations in Brazil that work with this illness. However, because the term still exists in the popular imagination, I believe it cannot be discarded or ignored. It must be acknowledged that patients might be familiar with the fact that *lepra*, though it may have many other popular associations (including dog mange, scabies, and other skin diseases) and stigma attached to it, can be synonymous with *hanseníase*.

Many of the patients I interviewed did not associate the terms *lepra* and *hanseníase*. If, upon diagnosis, patients are shielded from the fact that *lepra* and *hanseníase* can be synonyms, they sometimes find out about the connection between the two terms from friends and neighbors. Also, the term *hanseníase* was unknown to many patients before hearing it at the health post. For some patients, a disease with no set of associated images generated more fear and anxiety than *lepra* would have. One patient actually expressed relief upon finding out from a relative that *hanseníase* was leprosy. She was afraid that she had a form of cancer. Other patients thought that *hanseníase* was a euphemism for *lepra* and that healthcare professionals were trying to trick them. Leprosy detection campaigns and healthcare workers should consider working with both terms, with sufficient explanation of the curability of *hanseníase-lepra*.

**Leprosy and daily life**

Many patients I interviewed reported that leprosy affected many aspects of their lives at home, school, or work. Their experience with disease and disability was influenced in part by the type of employment they held. Women who were employed as domestic servants, for example, were sometimes fired when their employers discovered they had leprosy. Since
many domestic workers do not have contracts or belong to a union, they are more vulnerable to stigma. Several patients (men and women) worked in manual labour, which can be difficult or dangerous due to nerve damage and insensitivity in the hands and feet. In leprosy patients with nerve involvement, special precautions must be taken to prevent further damage to hands and feet, but these precautions (including a reduction in repetitive physical activity, use of orthopaedic shoes, soaking the feet, and special exercises for the hands) are not always practical or available for patients.

Because of disability and stigma (sometimes self-imposed), patients often change or limit their activities and socialization with others. Several patients mentioned at least one activity that had been curtailed because of leprosy. These activities included going to school or college, washing clothes, walking, swimming, playing soccer, going to the beach, karate, dancing, political/community activities, drinking, going on dates, and having sex. Sexual relations for many patients had ceased because of medication side effects, problems with leprosy reaction, and/or fear on the part of either person that leprosy could be transmitted in this way.

Several patients said that their mental health was also affected by leprosy and leprosy treatment. Not being able to get a diagnosis was reported as a cause of much anxiety. Once patients were diagnosed, fear of having to distance themselves from family members and friends, fear of losing their jobs, and fear of dependency and disability were other sources of sleepless nights and uncontrollable crying and sadness that some patients reported. Some patients associated sleeplessness and anxiety with the medicines they were taking. The problems of leprosy reaction and its treatment were also major causes of stress for many of the patients I interviewed. One patient I interviewed had attempted suicide four times after experiencing severe episodes of leprosy reaction and being abandoned by friends and family. Healthcare professionals must be aware of different aspects of leprosy treatment and how different disease processes might affect patients’ emotional as well as physical well-being.

Conclusions

In the course of my research in Brazil, I identified several specific areas in which advancements could be made to reduce the number of new cases and to improve the quality of patients’ lives. Early detection can be achieved through increased educational campaigns in the media and through better training of physicians in leprosy detection. Education about leprosy (in the form of public and media presentations and in the context of patient-healthcare worker interactions) should be informed by knowledge of popular beliefs about leprosy. For example, to combat certain negative images of leprosy, education should focus on the fact that leprosy does not come from dogs, does not come from eating fish or pork, does not cause limbs to fall off, and is curable. Leprosy education should also take into account the different perceptions patients might have of the terms for leprosy (hanseniae and lepra).

Patients must have greater access to medical services. Once patients reach the health post, physicians must be able to recognize their symptoms. Training in leprosy diagnosis should be required in medical schools in Brazil. Improvements can also be made in treating leprosy reaction. The options for treatment of reaction need to be expanded as well, since the drugs that are available today are problematic for many patients. Providing physical therapy services to prevent disability and to rehabilitate patients who are disabled are also very important parts of curing leprosy, as patients understand the definition of ‘cure.’ In terms of
improving the mental health status of patients with leprosy, psychological and social support services should be available to all patients. It would also be useful to explore new ways of talking about leprosy, leprosy reaction, and disability caused by these processes that would help patients to understand what is taking place in their bodies.

Through this research, I identified some of the challenges leprosy patients face in Brazil today. Although patients today have more freedom in terms of not having to fear confinement and institutionalization, as they did in the past, leprosy is still confining in many senses. It can restrict an individual’s ability to make a living, to socialize, and to enjoy life. It is my hope that through this study and similar research projects focusing on cultural and socioeconomic aspects of leprosy, ways can be found to increase detection of new cases and to minimize the problems patients have with the disease and its treatment.

References