

## SOCIAL ASPECTS OF LEPROSY IN BRAZIL

LYGIA M. CEZAR DE ANDRADE

*Oswaldo Cruz Foundation*  
Fiocruz - Rio de Janeiro - Brazil

Hanseniasis is a very serious social problem in Brazil because of its aspects of neurological disease with a great potential of deformation and physical incapacity. According to the most optimistic statistics, this physical incapacity reaches more than 40% of the patients.

Manaus, in the State of Amazonas, registers approximately 2,000 retirements per year due to the disease. This number includes the city and rural zone. This fact, of course, requires a lot of money from the Government, because of the high percentage of the patients' physical incapacity nowadays (Gonçalves, 1979).

Brazil has 80% of all leprosy cases registered in Latin America. According to the latest statistics, there were almost 200,000 cases registered in 1982 (Gonçalves, 1983), causing a very serious social problem to the country.

The physical incapacity of the leprosy patients brings psychic, professional, family and social consequences, as leprosy is one of most incapacitating diseases of medical pathology.

Almost half a century of sulphone therapy did not change the Brazilian social problem at all. Deformations continue to be the most important of the incapacities because of the psychological and social aspects involved.

People face the disease in just the same way they did in the past centuries before the clinical cure of the disease was achieved, causing the patient's segregation — segregation that is promoted by himself, his family and chiefly by the community in which he lives.

The reason for this segregation is connected as much with the word "leprosy" as with the leprosy patient, that is, as much with the cultural as with the social categories.

Categories are defined by cultural images, which are mental representations based on sensorial experiences. Leprosy as a cultural category is defined by cultural images which make that whole called leprosy. In general, this image presents similarities and discrepancies when cultural and scientific categories of the disease leprosy are compared.

In society, each person is socialized to adjust himself to the leprosy phenomenon, based on his cultural categories and not through scientific knowledge, which is restricted to a few specialists.

So, cultural images of leprosy that define it as a category represent the answer of culture to society's necessity to face this reality.

Domingos S. Gandra Jr. in his thesis: "Leprosy — An Introduction to the Study of the Social Phenomenon of Stigmatization", presents a number of interviews with 43 patients, 16 doctors and 640 common people held in 43 cities of Minas Gerais State. The interviews were carried on by the author and collaborating people trained for this purpose.

The group interviewed was composed of 351 women (57.6%) and 258 men (25%), a total of 609 persons.

Considering age, the majority of persons (35.8%) belonged to the 21-30 years age-group, and referring to school grade the complete secondary course prevailed (25.3%).

Using this thesis, we will try to focalize two main social aspects: the way healthy people act and think under their taboos; and how the leprosy community thinks about their cure, and also how they live with their taboos.

By analysing these interviews, we could see that there are many points of contact between both communities: healthy and patients, such as the idea of supernatural causes (resulting from the action of supernatural beings, through their own will or through human motivations like sorcery) and natural causes (or the various agents of Nature directly or indirectly appointed as causers of the disease). Heredity is one of the natural causes mentioned as provoking the disease.

Very important is the idea of *transmission* because it is related to *contamination*. Among the interviewed persons 24.8% think that leprosy is easily contagious.

Contamination is a belief based on an emotional inclination to think that the contact of the patients with their belongings or someone else's belongings can transmit the disease. This fact causes an automatic and unthoughtful reaction.

Leprologists are an example of this fact. Society and even other doctors look at them as if they were leprosy patients. All the difficulties these doctors must face are well known.

Pressed by other doctors and by the community, they cannot keep a private clinic. This prejudice is a hindrance to the new Brazilian sanitary policy of Hanseniasis integration into the general Health Services.

The interviews show that objects and even places utilized by the patients can contaminate healthy people (13.3%); it is a general belief that even the place where a patient has sat is capable of transmitting the disease.

The idea that the disease is incurable is very common (36.8%), but little by little things are changing, for 19.8% of the people interviewed think that leprosy has a cure and 12.3% answered that they didn't know if it is curable or not.

Concerning treatment the more persistent image is that of isolation. The images collected in the interviews about leprosy treatment are scarce. There are patients who believe that if they could transmit the disease to somebody else they would be cured.

As the social category of "lepers" is formed by individuals that present certain characteristics that lead society to identify them as having the disease classified in the cultural category of "leprosy", and as the images of the patients are fundamental to acknowledge the references society adopts for this classification, we have to know which are these images and how they are produced.

The production of these images happens independently of the contact with a leprosy patient. They are transmitted by a socializing process, formal or not formal, that influences society's behaviour and attitudes in the presence of the patient.

The informal socializing process has a great influence on the production of these images and on the way people will act. Literature, newspapers, cinema, radio, television and folk-tales condition not only the social category of "lepers" but also other images connected with other categories.

These associations of thought are very important for understanding the community behaviour toward leprosy patients. Patients' moral and physical characteristics are linked with psychological association. The same happens to emotional association.

By analysing global physical images of the patient, we can notice that the majority talks about some aspects in words such as: disgusting (11.8%), horrible (7.4%), with a bad smell (5.1%).

Even if the reality about the patient has been modified by the introduction of sulphone-therapy, cultural images remain almost the same.

There is still a big difference between leprosy patients' reality and cultural images about it, because these cultural images are based on old stories told in books, films, folk tales and other socializing processes, and have not yet been adjusted according to the present day scientific reality.

People generally keep in mind only certain aspects of these stories and myths. Time and place are forgotten but not the physical, psychological and even moral descriptions of the patients. They act as base and reinforcement of the conditioned "leper" images.

The most important aspects about cultural images of lepers are the deformities. Some parts of the human body when they are deformed are regarded as a characteristic of the social category called "leper" and have a greater meaning when we analyse the social process of someone's identification in the social category of leper.

According to the interviews, more deformities are memorized regarding some parts of the body: ear (6.2%), nose (13.5%), eyebrows (7.7%) and fingers (22.3%). We can observe that the descriptions of the patients found in books, magazines and personal talks are very similar to these here presented.

This shows that there are similarities between the update images and the reality of old descriptions.

The images of organic and functional alterations that call communities' attention are ulcers or "wounded body" (55.3%), *macules* or "spotted body", independent of their color (3.7%), insensibility (18.1%) and edemas or swelling in any part of the body (12.3%).

These data show that there is a stigma connected with the cultural category "leprosy" and the social category "leper". But in this social category will be included only patients that present characteristics agreeing with the images society has produced for this category, whether or not they are leprosy patients.

An interesting experiment was made with 100 people in Bambuí, in Minas Gerais State. Three photographs were shown: one of a tuberculoid leprosy patient, another of a lepromatous patient and the third of someone with American cutaneous leishmaniasis. When asked, most of the people pointed to the leishmaniasis patient as a leper.

Scientific and non-scientific literature is full of stories and facts that prove that leprosy produces similar emotional reactions in the majority of the cultures, whether occidental or oriental.

During the interviews many types of reactions were seen: from crying paroxysms to the violent dismissal of the interviewer, when the word "leprosy" or "leper" was mentioned.

The interviewers even reported that many nights during more than one month they dreamed about the disease, and in their dreams they saw themselves involved with leprosy patients in the different situations. This shows the strong connection of the stimulus with cultural images of the disease and its patients.

Even a better knowledge of the subject does not exclude emotional reactions against the disease or the patient. The best proof of this statement is the emotional reactions of doctors, even leprologists, against the disease. "Leprophobia" is still very common among them, notwithstanding the great progress achieved in the knowledge of Hanseniasis.

It is proved that even having rational information one can have emotional answers. We also know that the emotion produced by leprosy and leper categories generally does not depend upon people's will. Thus, even being rationally convinced, people can be led, by circumstances that cause psychological emotion, to act against their thoughts and desires. That is why some families hesitate to accept the return of a leprosy patient, even when paroled by the hospital and his doctor. Perhaps some sanitary campaigns are not successful because of these psychological emotions.

In general, the members of society cannot accept the fact of this disease occurring in their lives, because society considers leprosy an emotionally undesirable disease. So the diagnosis of the disease is received as an unexpected occurrence. They face the diagnosis as a confirmation of a disease the probability of which they have never thought about during their lives.

When asked: "Which disease are you most afraid of contracting?" 42.2% of the persons interviewed answered "Cancer", 24.8% answered "Leprosy", and 11.8% "Tuberculosis". But when questioned: "Between this disease (the one they mentioned) and leprosy, which one would you rather contract?", they generally changed their opinion and chose the one first rejected (75.3%). Only 20.3% preferred to have leprosy.

This fact shows the great fear the majority of people have of contracting the disease. They do not mention it from the beginning because they consider such eventuality a non-existent probability for them. When they hear the diagnosis, the trauma engendered is so great that it leads the patient to the desire to commit suicide as a first

behavior alternative. This happened in 18.7% of the interviews. But the number of suicides among leprosy patients is very small.

Emotional reactions can be an immediate search for isolation. Leprosy and leper categories produce an emotion that makes people change their contact situation by diminishing their proximity to other people, and even provoking their rejection. The intensity of the isolation can differ from person to person, but it always ends with solidarity patterns whether voluntary or institutional.

Seclusion attitudes vary according to the degree of certainty about the identification in the categories of "leprosy" or "leper".

Discrimination is an attitude through which society draws away from the patient or from any person it includes in the leper category. Unfortunately, discrimination processes, even with time variation, do not follow the scientific progress in the control of the disease. Society has always treated people included in the leper category differently, due to great fear, that is very far from the real dangers created by the disease. So, these discriminatory processes are something more than protection measures, they are part of what we call *segregation*. This segregation creates certain physical limits, that cause a spatial isolation for the group or person included in this category.

Even when society does not impose a formal isolation, as is now happening in Brazil, in view of the transformation of the Leprosaria, the majority of communities continue to impose space limits not only on the Hanseniasis patient, but on their contacts as well, particularly the most intimate ones.

In spite of scientific evolution and the legal measures taken, social behavior was not enough modified, notwithstanding the tendency against segregation on the part of doctors and the associations involved with patients.

While non-stigmatizing diseases promote or strengthen solidarity patterns, stigmatizing diseases like leprosy reinforce the rupture of such patterns.

For a social group to develop an emotional process as an adjustment mechanism to a certain category, it is necessary for the category to have a very special significance for this group: it must represent some *danger* or a deep *depreciation*.

To explain the emotional process related to leprosy and leper categories, the meaning of "danger" would not suffice, because there are other diseases involving much more danger that do not provoke such an emotional reaction.

Leprosy is a phenomenon common to the majority of human societies for many years, and it has awakened similar emotional reactions in all societies, regardless of their cultural differences.

If leprosy and leper categories are just the contrary of a basic or preponderant cultural factor, we must conclude that this factor must appear in all cultures. It must be a universal concept to human societies and also be fundamental to all of them.

The interviews have shown that physical deformation is very much feared. Society is afraid of contamination because of its results. So the basis of people's reaction is the effect and not the act of contamination.

Many diseases are more infectious than leprosy but they do not provoke the same reaction patterns as leprosy. So, infectiousness by itself does not explain these reactions, but the effects — the deformities — can be explained, because they are the fundamental content.

We must then observe how far cultural considerations regarding the human body can establish the basis of a valorization common to several cultures, to the point of establishing prevailing and basic values. The body is the concrete part of the human being and therefore all cultures have patterns of physical beauty that can differ from one culture to another, but are present in all of them. This demonstrates that the body is an object of aesthetic appreciation in all cultures, presupposing physical integrity at any time and in any human society.

The absence of this integrity makes the individual unadapted to the cultural models and forces him to look for a particular way of adapting himself to them.

In all cultures, we have beauty concepts and ways to make the body more beautiful. This proves that in all human societies, we have an appreciation of human appearance represented by the body. Leprosy deformities, as well as functional alterations, mainly the lack of sensibility, are deeply related to fundamental factors of the human being.

Based on these facts, it is understandable how leprosy and leper categories deny the human body integrity. If one's corporal image interacts with other people's images, we can conclude that such images, when representing a denial of the human formal or valorized appearance, produce reactions of unpleasantness, as even against one's will they are deeply connected to one's image.

Therefore we believe that the stigma which is connected with the leper and leprosy categories of all the cultures we know, could only be explained by the negation of physical integrity not only functional but

mainly in what concerns human aspects, that are fundamental factors in any cultural system.

It is based on these factors that people identify the members of a certain society. That is why leprosy is stigmatizing until we are able to develop a treatment capable of avoiding deformities and mutilations.

Before becoming sick the leprosy patient was a healthy person with the same points of view and taboos of the healthy community. So he is overcome by a very deep emotion when he hears the diagnosis of leprosy. This emotion is much more intense and permanent because the patient is at the same time the receiver and the promoter of the stimulus.

As a member of society, and participating in its culture, he has learned how to react and face the disease and the carrier of the disease. When he contracts leprosy, he knows beforehand how other people will react against him. So he begins to develop a psychological mechanism of negation in order to be protected from others.

In a Workshop on Control of Hanseniasis, Francisco A. Vieira Nunes, an ex-leprosy patient who is active in a movement for the reintegration of Hansenians, called MOHAN (Movimento de Reintegração do Hanseniano), reported on the Hansenian point of view regarding difficulties and ways of his reintegration.

The first difficulty concerned limitations, physical discomforts and deformities, which, besides turning daily routine into difficult tasks to be achieved, are the reason for the patient's isolation from society, that causes psychological traumas arising from the patient's defense mechanisms. This led the patient to change his name in order to protect himself and his family.

Next, referring to deformities, Francisco quotes *esthetics*. The loss of esthetics in the hands, feet, and especially in the face, besides causing psychological traumas in the patient, is always a reason for indiscreet questions frequently asked by the healthy community, and throughout the patient's life. After a certain time this situation becomes completely intolerable for the majority of the patients.

The financial question is also a very important problem. Lepers are generally poor and have great difficulties in providing money for their families. These problems become even worse because of their physical discomforts and limitations. Pensions and retirement pay given by the Social Welfare Ministry are not sufficient. Since poverty is very common among leprosy patients, they generally feel like marginals.

People's fear and prejudice against leprosy patients have a strong influence on the patients' isolation from society and on their fear to



have any kind of relationship with other people. They feel ashamed of going to a party or to a social meeting; especially they feel ashamed in their place of work because they feel insecure and afraid of the community's reaction. This fact causes a psychological trauma almost without solution.

The fear demonstrated by doctors and other health professionals makes patients much more insecure. They feel ashamed as if they have a *terrible* disease. If these professionals have this kind of reaction, what about ordinary people? When the health professional accepts the patient, his example makes things easier for the patient's acceptance by his family and community.

The hasty closing or transformation of the leprosaria to other purposes, without previous programming, causes a serious social problem, mainly for those patients that had lived there for a long time, many of them for almost all their lives, having completely lost all links with the outside world and having even been rejected by their families. Without a place to go to or means to survive, they hide in the so-called "vilas" that are an extension of the leprosaria but without any substructure, organization or government support.

However, good results could be obtained with good planning and some financial resources, as happened in an experiment conducted in the city of St. Louis, Maranhão State, after the closing of its leprosarium, and related by Jorge de Oliveira Macedo in his lecture on "Concrete cases of Colonies Closing" dealing with the recuperation of "Vila Nova" that was transformed into a suburb of St. Louis City. This splendid experiment, carried out with CERPFA's (Comissão Evangélica de Reabilitação de Pacientes de Hanseniasis) precious moral, social and financial support, shows that a well planned and a well conducted work can produce excellent results such as the fair interplay between the healthy and the sick community, there achieved without commotion.

Through well conducted Health Education, the patients became so conscious of the indispensable necessity of taking the prescribed medicine with permanent continuity that no new leprosy case was detected in a population of 2,500 persons.

Such experiments should be repeated in others of the many proliferating "Vilas" in Brazil if we could also count on the help of other philanthropic entities like CERPFA.

This would be a great step towards the solution of the social question created by leprosy prejudice and towards the control of the disease in our country.

## BIBLIOGRAPHY

- GANDRA D. S. JR., *A LEPROSA -- Uma Introdução ao Estudo do Fenômeno Social da Estigmatização*, Thesis, Faculdade de Filosofia e Ciências Humanas, UFMG, Belo Horizonte, 1970.
- GONÇALVES A., *Ações em Saúde*, São Paulo. Editora Papiro, 1979.
- GONÇALVES A., *Relatório das Ações/Atividades de 1983*. Divisão Nacional de Dermatologia Sanitária, Ministério de Saúde, Brasília (DF).
- GONÇALVES N. N. S., *Recursos Humanos em Hanseníase*. Workshop on the control of Hanseniasis, DNDS, MS/PAHO-WHO. Brasília (DF) Novembro 20-25, 1983.
- MACEDO J. O., *Casos Concretos de Desativação de Colônias*, Workshop on the control of Hanseniasis, DNDS, MS/PAHO-WHO. Brasília (DF) Novembro 20-25, 1983.
- NUNES F. V., *O Ponto de Vista do Hanseniano sobre sua Reintegração*. Workshop on the control of Hanseniasis, DNDS, MS/PAHO-WHO. Brasília (DF) Novembro 20-25, 1983.