

## Leprosy as a Neglected Disease and Its Stigma in the Northeast of Brazil

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Hansen's disease is an infectious and degenerative chronic disease with a high potential for incapacitation. Due to the explosive epidemic of leprosy cases worldwide (especially in Brazil), the social difficulties faced by these patients are an important subject for research. This work aimed to identify the stigma experienced by these patients. The qualitative research for this study was completed at the National Reference Centre in Dermatology in Fortaleza. The study took place in northeast Brazil from September 2010 to November 2012. The research subjects included 20 people with Hansen's disease of both sexes between 20 and 70 years old. The data collection consisted of a semi-structured interview. From the discourse analysis of the participants, several changes experienced by persons affected by leprosy were noted from the empiric categories emerged. Changes occurred in the family, the receptiveness of neighbours and co-workers and the patients' social lives were experienced by the persons affected after the diagnosis of Hansen's disease. From the data obtained, it was concluded that the patients are stigmatised. Sometimes they are forced to hide from relatives, friends, neighbours and co-workers. Despite their social exclusion, they believe their isolation is justified. Leprosy is a chronic, degenerative and curable infectious illness that continues to be a serious public health problem, mainly in the poorest region of Brazil.

**Key words :** Leprosy; Hansen's disease; Stigma; Infectious illness

### Introduction

Hansen's disease is an infectious and degenerative chronic disease with a high potential for incapacitation. According to official reports received from 115 countries and territories, the global registered prevalence of leprosy at the end of the first quarter of 2013 stood at 189,018 cases, while the number of new cases detected during 2012 was 232,857. Currently, Brazil is the country

with the largest number of cases in Latin America is the second in the world in absolute number of cases of leprosy (WHO 2010).

The treatment of leprosy in Brazil has gone through similar stages to those in other countries. By the year 1951, the confinement of patients with Hansen's disease was mandatory. According to reports, patients were hunted and taken as prisoners in one of the 33 colonies in the country

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(Barreto 1942). After 1951, the use of 'sulfonas' meant that admission to hospitals was no longer compulsory. Since 1951, the treatment of patients has become the exclusive responsibility of governmental health programs.

The country has taken new health actions related to the disease since 1995. In 1999, it ratified a commitment to reduce leprosy by 2005, with a goal of less than one case for every 10,000 inhabitants. This goal has not been achieved thus far. In some regions, there are currently more than 14 cases for every 10,000 inhabitants, second only to India (Magalhaes and Rojas 2007). In Brazil, Hansen's disease requires notification. In 2008, Brazil had the largest number of relapses reported worldwide (Fine 2008). In 2011, 228,474 new cases of leprosy were detected in the world. Brazil ranks second in the absolute number of cases behind only India (WHO 2011).

After the commitment to eradicate Hansen's disease in 1991, there was a reduction in the prevalence by 60%. However, after this period, the detection of new cases increased by more than 100% (Ragazzi et al 2006).

Not only in Brazil, but in every country where leprosy is prevalent, there is a history of prejudice and isolation towards leprosy patients. Compulsory admission of people with Hansen's disease no longer occurs, but the stigma still persists. The stigma is more resistant than the disease, and it influences patients' self-esteem (Araújo 2003).

The historical isolation of patients served to control the endemism of the disease. However, isolation increased the fear and prejudice associated with the disease. Deformities, visible ulcerations, false concepts about transmission and misunderstandings about the possibility of

cure still lead to rejection of patients by society and health professionals. Stigma not only affects people with visible signs of leprosy, but also those who are diagnosed without visible signs (Salazar 2001).

The fear of contamination comes from a lack of knowledge, and it can be the main cause of family disaggregation, and underemployment. The psychological problems related to the disease include rejection and low self-esteem (Claro 1995).

Due to the explosive epidemic of leprosy cases worldwide (especially in Brazil), the social difficulties faced by these patients are an important subject for research. This work aimed to identify the stigma experienced by these patients.

### **Material and Methods**

The research was conducted, from 2010 to 2012, through a qualitative approach using the theoretical sociology of Erving Goffmann (Goffmann 1963). He studied about the stigma and its consequences in the personality and in the social hole of the individual. "*Stigma* is an illuminating excursion into the situation of persons who are unable to conform to standards that society calls normal. Disqualified from full social acceptance, they are stigmatized individuals. Physically deformed people, ex-mental patients, drug addicts, prostitutes, or those ostracized for other reasons must constantly strive to adjust to their precarious social identities. Their image of themselves must daily confront and be affronted by the image which others reflect back to them" (Goffmann 1963).

The research took place at the National Reference Centre for Dermatology. The centre is located in

Fortaleza in northeast Brazil. This centre is recognised by the Brazilian Health Department as a national reference unit for the assistance of patients with Hansen's disease. The centre reports an average of one thousand diagnoses per year. Currently, about 1,300 patients are being treated.

The subjects for the study were patients with Hansen's disease. Patients were selected 10 of each sex, at random regardless, age or signs of the disease. All patients were older than 20 years of age and were still undergoing treatment. All patients signed a free and clarified consent form. The patients were selected through choice of convenience sampling that is a non-probability sampling technique where subjects are selected because of their convenient accessibility and proximity to the researcher. The criteria used for stopping the research were the "saturation" that the point at which no new information or themes are observed in the data.

The data collection consisted of two parts. The first part obtained information regarding age, marital status, years of education and occupation. The second part consisted of a semi-structured interview with open questions answered through an individual and informal conversation. The contents of the interview were recorded, transcribed and analysed. The themes in the questionnaire concerned the patient's perception of the disease, the attitude of the family and of the people who were encountered in the home and professional environments.

#### **Ethical aspects of the research**

The project was evaluated and approved by the Ethics Committee in Research at the University of Fortaleza. The research obeyed Resolution

196/96 of the Regulatory Guidelines and Rules for Research involving human beings of the National Council of Health of Brazil. The patients' rights of spontaneous participation and anonymity were respected.

#### **Results and Discussion**

Since this is a qualitative research results to come together to discussion.

##### **Characterisation of the research subjects**

The studied group consisted of 20 patients (ten female and ten male). The interviewees' age varied from 20 to 70 years (mean age of 42.3 years, and standard deviation  $SD \pm 14.9$  years). As for marital status, nine (45%) were single, eight (40%) were married, two (10%) were separated and one (5%) was a widower. Regarding education level, ten (50%) patients had between 10 and 12 years of study, nine (45%) between one and nine years of study and one (5%) did not have any education. No participant had any graduation. Regarding occupation, eleven (55%) were labourers seven (35%) were unemployed and two (10%) were pensioners.

After analysing the interviews, we identified the following categories: (1) The changes that occurred in the family after the diagnosis of Hansen's disease; (2) The attitude of neighbours and co-workers to the diagnosis of Hansen's disease; (3) The consequences in the patient's social life.

##### **Changes that occurred in the family after the diagnosis of Hansen's disease**

When questioned about the changes that occurred in the family after the diagnosis of Hansen's disease, most (55%) of the participants said that there had been behavioural changes. Specifically, there were reactions of religiosity, prejudice, guilt, fear and escape.

### **Religiosity**

My family was very shocked. However, today they are used to it. Every day my mother says some prayers. She says these prayers for me and I accept them. (Participant 4)

The religiosity is interpreted as a return to the spiritual feelings that Hansen's disease is a case of impurity. Furthermore, its cure is related to a miracle from a divine power. In Brazil, the mosaic of cultures and ethnic backgrounds is reflected in the population's religiosity, that is strongly present in Brazil and especially in the Northeast of the country.

### **Prejudice and aversion**

No. Only my husband teases me once in a while. He calls me a leper. When he is angry he does this. (Participant 14)

Regarding the people in my house, it has been a bit weird. Although they haven't kept away from me, I noticed certain changes. For example, they don't eat off the same dish.

Some interviews revealed that family members were avoiding the patients. There was deception and fear of getting the disease, both of which are characteristics of the stigma experienced by patients with Hansen's disease.

The family is a fundamental institution that takes care of its members. When a family member is threatened by a disease, it is in the family that he/she will look to for support in the face of suffering and low self-esteem. According to Barbosa and Giffin (2007), the family is a unit of the society in which people are linked by affective ties and by common interests. It is also in this structure that we accomplish reproduction and production.

Through the results of the study, it is noted that

Hansen's disease has a stigmatising stereotype. This stigma makes some patients hide their disease from their family, spouse, neighbours and work. In some cases, patients only allow the closest people around them know about the situation.

Any alterations in behaviour will invariably affect the family of a person. The author emphasises that the occurrence of a disease in a member of a family increases stress. In some cases, families may not be able to deal with the stress effectively (Ponte and Ximenes-Neto 2005).

Goffman (1963) stated that stigma is best explained by considering "deviating notions" as references (i.e., deviation from the predominant or estimated rules). Susman (1994) defines stigma as any notion that evokes negative or punitive response from an individual or group. Conditions that are not enabling are often stigmatising since they evoke negative or punitive responses.

It is important to note, from the results of the study, that the participation of one's family is indispensable in the treatment of Hansen's disease. Hansen's disease patients need people to trust, to give them support, to encourage them, to strengthen them, to help them overcome the stigma and discouragement and to help them maintain the treatment.

### **Neighbours' and co-workers' attitude in the face of the diagnosis of Hansen's disease**

When questioned about the effects of Hansen's disease on the patient's neighbourhood and work, most participants stated that there were no great changes in the behaviour of these people. However, the researchers realised that the stigma permeated some depositions.

My colleagues - most of them don't know. I am not going to tell, am I ? Some colleagues who know

about the disease don't bother, but others keep a little distance. They don't come close to us. I feel some rejection already. (Participant 3)

Well, I wasn't so well-known on the street, but after I caught this disease everybody started to stare at me...but I don't take it seriously, you know? (Participant 6)

According to participants' some of them hide the disease from neighbours and co-workers for fear of their reactions. They mostly fear dismissal and the prejudice that they might suffer. This aspect of stigma is labelled as self-stigmatisation.

According to the concept of stigma developed by Goffman (1963), the socio-cultural manifestation of stigma has three fundamental parts, including body abominations, flaws in character and social provenience.

It was notable that there were prejudices in people's interviews. Even in these modern times, prejudice is still found in individuals' everyday lives. Stigma still exists when patients say they have been called "lepers" for being Hansen's disease patients.

Some individuals have had their identity "stained" for having attributes that are considered socially unacceptable by members of the society. For some time, these attributes have been associated with shame, indignity, disfavour, and blame. In this regard, the stigma of individuals and groups varies in multiple dimensions. Categorically, different acceptability is shown towards varying individuals or groups (Takahashi 1997). For this author, rejection and violent reactions of a community towards individuals are viewed as more than selfish and exclusionary actions. As a result of structured social relations, people and places are often considered "abnormal." This attitude creates labels that stigmatise and

marginalise specific groups (Takahashi 1997), and finally as one of the criteria of delay in diagnosis (Nicholls et al 2005, Guerrero et al 2013).

### **Repercussions of Hansen's disease in patients' social lives**

Regarding the repercussions of the disease in patients' social lives, we identified great changes in patients' everyday lives after diagnosis. The depositions below demonstrate these findings:

After these problems started to appear in my skin, I started to spend less time outside. (Participant 1)  
My life stayed this way, the folks stayed away from me. We can see this. Some of them completely stopped going to my house. Only some of them keep on going there. (Participant 2)

Based on the reports, we found that Hansen's disease brought about deep changes in the patients' social lives. The diagnosis of Hansen's disease aroused feelings of low self-esteem, nervousness and preoccupation as well as a tendency towards isolation. The patients who presented with visible physical deformities experienced even more pronounced stigma. From the reports the researcher didn't find any relation between patients background (age, marital status, occupation and education) and the severity of the stigma experienced.

According to Goffman (1963), individuals facing stigma who could easily be received in everyday social relations tend to push away those who are close to them, destroying relationships and taking away from their other attributes. Stigmas result from prejudice, pre-conceived ideas, consolidated thoughts/beliefs and socio-individual expectations.

The interviewees in this study demonstrated discomfort as a result of skin colour alteration

from treatment. These changes even further contributed to their isolation. In many cases, a patient's altered appearance resulted in speculation, curiosity and prejudice.

Even when patients were able to hide their disease successfully, concern about its discovery served as a constant torment. This anxiety made life harder and decreased the quality of life of the patients (Bottene and Reis 2012).

The repercussions of Hansen's disease definitely interfere with the everyday life of individuals who suffer from it. Hansen's disease is a constant menace. The uncertain success of treatment and patient's preconceptions make it a particularly difficult diagnosis (Nicholls et al 2005, Guerrero et al 2013). From our study, it appears that suffering, abandonment, deformities and psycho-social problems frequently occur.

#### Final Considerations

This study demonstrated that there are changes in the attitudes of Leprosy patients' families as a result of the disease. Furthermore, there are repercussions brought about by the disease in the patients' everyday lives. We observed feelings such as annoyance, silence, stigma, and aversion. These feelings can contribute to the failure of treatment, noted by a poor adherence to the therapies.

Hansen's disease brought about changes in the lives of people who underwent treatment. Emotions were evident in the speeches of the respondents. The patients mentioned feelings of revolt, sadness, anxiety, and denial when dealing with the disease and its attributes. Stigma concerning the disease was very evident in the depositions, illustrating that stigma towards leprosy is still present in society.

Measuring and understanding the effects of

leprosy in the patients served to illustrate the patients' daily lives. This study highlighted the bio-psychosocial, cultural and economic contexts of the disease. This study allowed for a closer view of the intimate lives of the studied people. Overall, we revealed how patients suffer from the psychological aspects of the disease.

In conclusion, these individuals need more attention. The patients need help in clarifying their doubts and easing their suffering. Patients need to be seen by others as normal people. It is necessary and important that society is educated, since most people still have prejudice. In fact, many people are unfamiliar with the forms of transmission and are unaware that the disease is curable. The obtained data enabled us to understand the reasons why Hansen's disease patients face social isolation. Their isolation is a consequence of social exclusion.

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