v. 2, n. 69, 2022

International
Journal of
Health
Science

STIGMA ANALYSIS IN PATIENTS WITH LEPROSY

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DOI 10.22533/at.ed.1592692215117

Abstract: Leprosy (HD) is a chronic disease, affecting people of any sex or age group, with a long clinical course and which, when left untreated, can cause deformities/physical disabilities, making its impairment visible, which can lead to social stigma. We sought to analyze the report of situations of social stigma in leprosy patients at the HD referral outpatient clinic in Sorocaba/SP. We applied the Brazilian version of the Explanatory Model Interview Catalog (EMIC) – Stigma Scale for people with HD in 37 leprosy patients; we also made an open question to describe some experience in this sense. Quantitative results were evaluated with Mann-Whitey and Kruskal-Wallis tests. We had 22 patients (59.46%) who said they had never suffered a situation of social prejudice due to leprosy. The statistical correlation between different clinical variables (gender, age, education, color, clinical stage of the disease), as well as the correlation between each of the clinical signs/symptoms of HD and the final EMIC score did not show any statistically significant association. Despite these findings, the existence of social stigma is clearly a problem that interferes with a better result in the eradication of the disease, and must be corrected by the health authorities.

Keywords: Leprosy. Social stigma. Preconception.

INTRODUCTION

Leprosy (DH) is part of the National List of Notifiable Diseases and constitutes a serious public health problem in our country, as we have more than one case for every 10,000 inhabitants. Brazil is the country with the highest number of cases in the Americas and the second in number of cases in the world. (Health, 2020)

It is a chronic disease, capable of affecting people of any sex or age group, whose long clinical course, with a slow and progressive evolution that, when not properly treated, can cause deformities and physical disabilities, often irreversible, making its commitment, which can lead to social stigma. ("Leprosy", 2011)

Local sensitivity changes that may be associated with erythematous, hypo- or hyperchromic patches on the skin, hair loss and absence of perspiration are described findings of HD. When the nerve in an area is affected, hypoesthesia, muscle hypotonicity and finger retractions appear, with the development of physical disabilities. In the acute stages, nodules and/or edema may appear in the coldest parts of the body, such as ears, hands, elbows and feet. ("Leprosy", 2011) Neural involvement is the main reason for the deformities that reinforce prejudice against leprosy patients. (Araujo Silva, Alves Ribeiro and Brito Oliveira, 2016)

In the lepromatous phase, its most widespread form, it is difficult to separate normal from damaged skin, which may compromise the nose, kidneys and male genitalia. ("Leprosy", 2011)

Most of the reported cases (78.2%) are multibacillary (MB) forms, that is, those that have the greatest potential to determine the appearance of sequelae and, consequently, the physical characteristics that are peculiar to the disease, which could lead to prejudice. (Health, 2020)

Treatment with multidrug therapy is effective in reducing the microbial load, preventing the progression of the disease, but it does not have a great impact on social discrimination against the disease or affected people. (Dantas et al., 2020) This is probably due to late diagnosis, in which most are already in the advanced forms, which are the most mutilating, determining irreversible sequelae. Thus, there is still a large contingent of individuals with some degree of physical impairment that characterizes the most serious situations of HD.

In addition, millenary prejudices and stigmas still persist today, preserved by historical, cultural and mythological aspects regarding its origin and transmission of this disease. The term “leprosy” is very old and is often related to something bad, almost like a curse, because the sick were seen as sinful, dirty people who deserved to be punished for their impure acts. (Brown, 2003)

This ancient concept produced isolation policies worldwide. In Brazil, from 1924 onwards, the federal government took control of HD through compulsory hospitalization under the argument of protecting a healthy society from contagion. After the publication of the National Plan to Combat Leprosy, in the 1930s, the construction of leprosariums spread throughout the country. They were large properties constituted as small towns, with housing, city hall, police station, jail, theater, church, registry office, cemetery and other buildings that allowed life to happen inside without the need for the inhabitants of the leper colony to have contact with the outside world. The space was divided into two areas, usually isolated by a wall: the “clean area” or “intermediate area”, intended for the employees’ residences, and the “dirty area” (wards) or “sick area”. (Borentein, Süssking Mirian, Padilha, Itayra Maria, Costa, Eliani, Gregório, Vitória Regina Petters, Koerich, Ana Maria Espindola, 2008)

Even with the formal abolition of compulsory internment in 1962, the former “leprosariums” were responsible for an excluding treatment over the centuries and, as a consequence, led to their social marginalization. (Borentein, Süssking Mirian, Padilha, Itayra Maria, Costa, Eliani, Gregório, Vitória Regina Petters, Koerich, Ana Maria Espindola, 2008).

Considering that social representations are continually constructed and expressed in the speech and behavior of individuals, when a representation affects the social identity of others, repelling them from the spaces of conviviality and refusing to assign them the same, over time this can become the root of social stigma. (Schilling and Miyashiro, 2008)

According to analyzes proposed by Polish sociologist and philosopher Zygmunt Bauman, the “strange” and “indefinable” are denied self-confidence and self-pity (Schilling and Miyashiro, 2008), suggesting that social stigma can often become internalized. by the patient. (Rhaisa Gontijo et al., 2011)

We were interested in knowing how HD patients report living with social stigma through their observational or personal experiences regarding their disease in the region of Sorocaba, because for many years we had a leprosarium unit (Hospital Pirapitinguí – Hospital “Dr. Francisco Ribeiro Arantes”), which historically housed a huge community of leprosy patients.

METHODOLOGY AND CASUISTRY

Exploratory, descriptive study, with quantitative and qualitative approaches, carried out with 37 patients treated at the Policlínica Municipal de Sorocaba, older than 18 years, confirmed diagnosis of HD and preserved cognitive capacity.

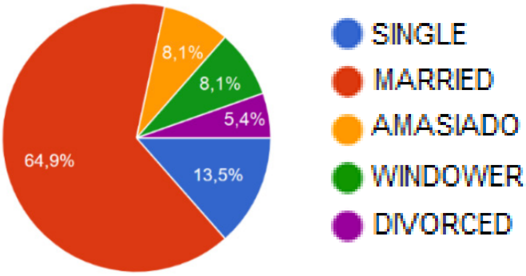
Clinical information was collected, detailing it.

Applied to the Brazilian version of the *Explanatory Model Interview Catalogue (EMIC) – Stigma Scale* for people with HD, with 16 objective and alternative questions elaborated on the Likert scale. For qualitative evaluation, we asked whether they had already suffered prejudice for being a HD patient, describing the situation.

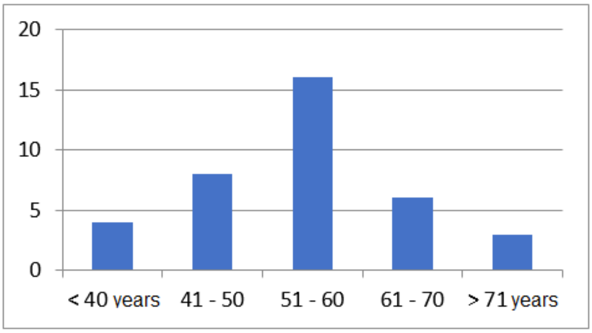
The results were analyzed in R4.1.0. We used the Mann-Whitey and Kruskal-Wallis U test for quantitative results. Minimum significance levels were considered when the p-value was less than 5% or 0.05.

RESULTS

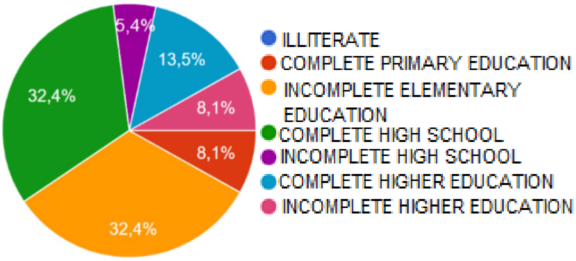
Thirty-seven patients were interviewed, 64.86% female and 35.14% male, being 21 white, 13 brown and 3 black. Marital status, age and education are represented, respectively, in graphs 1, 2 and 3.



Graph 1 - Marital Status.



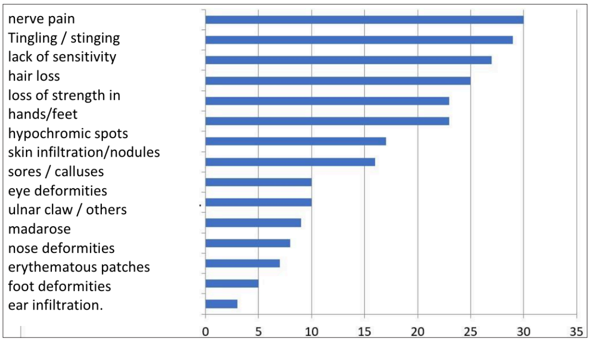
Graph 2. Age distribution of HD patients interviewed.



Graph 3 - Education of HD patients interviewed.

The analysis of medical records revealed that most patients were in the 'Borderline/ Dimorphic' phase (69.44%) at the time of diagnosis, and currently, in the 'unknown' clinical phase (58.33%).

Except for two patients, all the others (94.44%) had physical sequelae related to HD, some of them with more than one lesion, whose description is presented in Graph 4.



Graph 4 - Patients who have sequelae or lesions typical of leprosy.

The analysis of responses indicates the sectors most committed to the assessment of stigmatizing conditions. The highest score would be 48 points, meaning no stigmatizing situation. We obtained a median sum of 12.00 (1st Quartile 6 and 3rd Quartile 16), as shown in Table 1.

Of those interviewed, 59.46% do not remember having suffered prejudice because they have HD, however, some reports suggest exclusionary situations because of the disease. In the others, it was possible to obtain some reports that unequivocally described situations of stigma, as in the following examples:

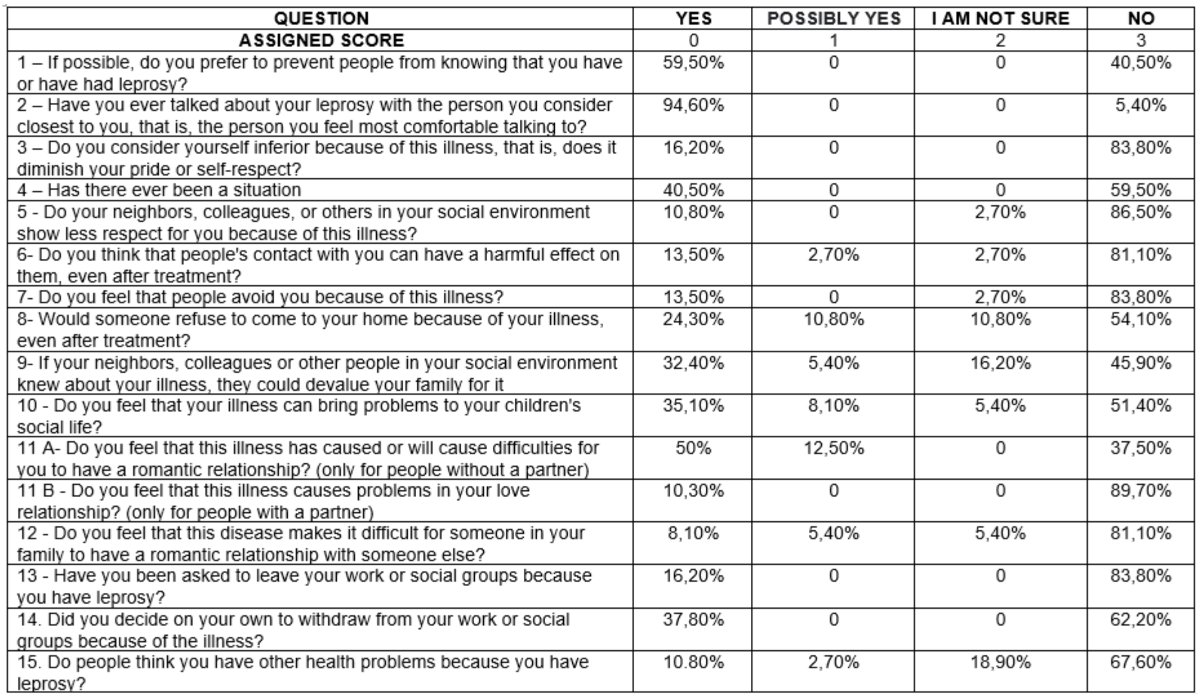
> *"...After telling the family, my sisters-in-law moved away from me, they don't go to my house anymore, they don't even visit me. After that, I decided not to tell anyone else...."*

or

> *"...My daughter avoids being with me because she is afraid of getting it..."*

DISCUSSION

According to the anthropologist and sociologist Erving Goffman, the notion of stigma comes from the Greeks with reference to bodily marks produced, to indicate the



QUESTION	YES	POSSIBLY YES	I AM NOT SURE	NO
ASSIGNED SCORE	0	1	2	3
1 – If possible, do you prefer to prevent people from knowing that you have or have had leprosy?	59,50%	0	0	40,50%
2 – Have you ever talked about your leprosy with the person you consider closest to you, that is, the person you feel most comfortable talking to?	94,60%	0	0	5,40%
3 – Do you consider yourself inferior because of this illness, that is, does it diminish your pride or self-respect?	16,20%	0	0	83,80%
4 – Has there ever been a situation	40,50%	0	0	59,50%
5 - Do your neighbors, colleagues, or others in your social environment show less respect for you because of this illness?	10,80%	0	2,70%	86,50%
6- Do you think that people's contact with you can have a harmful effect on them, even after treatment?	13,50%	2,70%	2,70%	81,10%
7- Do you feel that people avoid you because of this illness?	13,50%	0	2,70%	83,80%
8- Would someone refuse to come to your home because of your illness, even after treatment?	24,30%	10,80%	10,80%	54,10%
9- If your neighbors, colleagues or other people in your social environment knew about your illness, they could devalue your family for it	32,40%	5,40%	16,20%	45,90%
10 - Do you feel that your illness can bring problems to your children's social life?	35,10%	8,10%	5,40%	51,40%
11 A- Do you feel that this illness has caused or will cause difficulties for you to have a romantic relationship? (only for people without a partner)	50%	12,50%	0	37,50%
11 B - Do you feel that this illness causes problems in your love relationship? (only for people with a partner)	10,30%	0	0	89,70%
12 - Do you feel that this disease makes it difficult for someone in your family to have a romantic relationship with someone else?	8,10%	5,40%	5,40%	81,10%
13 - Have you been asked to leave your work or social groups because you have leprosy?	16,20%	0	0	83,80%
14. Did you decide on your own to withdraw from your work or social groups because of the illness?	37,80%	0	0	62,20%
15. Do people think you have other health problems because you have leprosy?	10.80%	2,70%	18,90%	67,60%

Table 1: Answers of the objective questionnaire, in percentage of each one of the interviewees for the respective alternatives.

condition of exclusion from the normal social circles. Currently, he confirms that the concept is applied to cases in which a characteristic is identified as undesirable/inferior. (Schilling and Miyashiro, 2008)

The philosopher Agnes Heller says that all prejudice originates in the formation of ephemeral judgments, which are endowed with a particular affection that makes them more resistant to being corrected by experience, knowledge or moral decision. (Barreto et al., 2013; Miranda et al., 2005)

The fear of contracting the disease or becoming disabled is influenced by stereotypes. Added to this, Brazil offers little space for non-productive people. (PAHO/WHO, 2019; World Health Organization, 2017)

Physical/work limitations are common in HD patients, especially with late diagnosis, long evolution and inadequate treatment. Nigerian studies suggest that stigma is greater in the inability to contribute financially. (Fonseca and Garcia, 2014)

Questions 13 and 14 of the EMIC focus on the work situation, however, we did not observe positive responses more frequently than in the other domains.

Although 94.44% of respondents had one or more sequelae, less than half (40.54%) reported having suffered a situation of social stigma because of the disease.

The statistical correlation between different clinical variables and the final EMIC score did not show any significant association. In addition, individualized analyzes by findings of HD sequelae were also not reflected in greater stigmatizing situations.

However, when analyzing the testimonies, we noticed situations of suffering that contribute to social isolation. The reports of those who denied having suffered a stigma situation also reflect the hidden stigma, as in these cases there was no disclosure of their condition. (Nunes, [n.d.])

CONCLUSIONS

Based on our results, we believe that social stigma in individuals with HD can occur in the community, at home or at work, but probably its perception is due to other individual conditions besides physical characteristics. Perhaps in new research with instruments that allow characterizing depressive situations, applied together with the EMIC, it could solve these doubts.

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