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IMPACT ON THE SOCIAL LIFE OF LEPROSY PATIENTS WITH LEPROSY REACTIONS

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ABSTRACT

The study aimed to understand the impacts on the social life of leprosy patients with leprosy reactions. This is a qualitative study, conducted at a university hospital located in a capital in northeast Brazil, in the period from December 2017 to January 2018, with five patients monitored in leprosy reaction. Data were collected through a semi-structured interview and subjected to content analysis. After analysis, four categories emerged: changes in the life of the person affected by leprosy with leprosy reaction; the stigma brought by it and its impacts on the routine of the bearer of the leprosy reaction; the family context in the patient's life and the experiences of the person affected by leprosy in leprosy reaction in the work environment. Despite the information linked through health education works, there is still a strong social stigma tied to the disease, which generates significant negative impacts on daily life, isolating and socially excluding the patient, who becomes a prisoner of his/her illness.

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INTRODUCTION

Leprosy constitutes a serious public health problem and is a chronic disease that can cause irreversible and stigmatizing physical injuries. The people affected by this disease are likely to be excluded from their social relationships and daily activities (Simões *et al.*, 2016). Data show that the overall prevalence of leprosy has reduced, because in mid-1980, there were more than five million registered cases and in 2015, there were less than 200,000.

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The prevalence rate was 0.23 per 10,000 inhabitants, with 171,948 cases of leprosy in treatment at the end of 2016. During the year, 214,783 new cases (2.9 per 100,000 inhabitants) were recorded globally (WHO, 2017). In Brazil, 25,218 new cases were recorded in 2016, with general detection coefficient of 12.23 cases per 100,000 inhabitants, which represents an area of high general detection coefficient. The prevalence rate was 1.10 per 10,000 inhabitants (Brazil, 2017). Maranhão is considered a hyper-endemic state, with general detection rate of 47.43 cases per 100,000 inhabitants and records of 3,298 new cases of the disease in 2016, a number lower than the one registered in 2015, when there were 3,540 new cases of the disease with detection rate of 51.27

cases per 100,000 inhabitants (BRAZIL, 2017). During the evolution of the disease, leprosy reactions episodes can happen. These reactions appear as exacerbated response of the immune system triggered by *M. leprae* antigens. The reactions are classified in reaction type 1, in which there is a thickening of the nerves and emergence of new lesions or exacerbation of old lesions, and type 2, whose main characteristic is the appearance of erythema nodosumleprosum (CUNHA *et al.*, 2013). Leprosy reactions can occur before and, more often, during or after the treatment. The frequency of these outbreaks relates to the clinical form and initial bacilloscopic index. The reactional are present in approximately 10 through 50% of cases of leprosy, especially in multibacillary forms, and is responsible for the abandonment of treatment and physical disabilities (TEIXEIRA *et al.*, 2010). In this context, the reduced quality of life and the stigma experienced by the individual affected by the disease is even more accentuated in the presence of physical disabilities arising from the reactional states. These factors directly interfere in the physical and psycho-socio-economic conditions of these people¹⁰. In addition to the historical stigma, leprosy reactions can be the greatest obstacle faced by these patients, since they are the main risk factor for the development of physical disabilities and permanent disabilities (QUEIROZ *et al.*, 2015). Understanding the impacts of the disease arising from physical limitations that may arise from leprosy reactions and how these issues interfere with the social aspects related to family and social nucleus are of fundamental importance and contribute to understanding how these issues affect positively or negatively in the construction of concepts about the disease (SILVA *et al.*, 2014). From these reflections, the following guiding question arose: What are the social impacts experienced by the person affected by leprosy with leprosy reaction?. Therefore, the objective of this study was to understand the impacts on the social life of leprosy patients with leprosy reactions.

METHODOLOGY

This is an exploratory study with a qualitative approach. The research was conducted at a university hospital, located in a capital of the Brazilian northeast, reference for people with leprosy in monitoring of the reaction picture. The study was carried out in the period from December 2017 to January 2018. Five individuals with leprosy reactions participated in the study, selected by means of non-probabilistic convenience sampling, due to the small number of patients in follow-up of leprosy reactions in the data collection period. The inclusion criteria adopted were: having leprosy in leprosy reaction, aged over 18 years and being under outpatient treatment at the hospital. Individuals with any condition that prevented the verbal communication were excluded from the study. As part of the methodological procedures, there were two meetings with each participant, and the data collection instruments were a guide containing socio demographic characteristics and semi-structured interview. To ensure data reliability, the interviews were audio-recorded with participants' consent and fully transcribed. In order to ensure anonymity, the participants were identified with the letter "E" (*entrevistado*, interviewee in Portuguese), followed by the number corresponding to the order of the interviews, the letters "M" or "F" for male or female and another number regarding age. The speeches were transcribed, organized and analyzed by means of content analysis. The content analysis is a set of techniques for communication analysis, seeking, through systematic and objective procedures

of description of the content of messages, indicators (quantitative or not) that allow inferring the knowledge regarding conditions of production/reception of these messages. This research technique allows replicating and validating inferences about the data for certain context, by means of scientific and specialized procedures, in addition to seeking an interpretation of the qualitative data encrypted (BARDIN, 2016). The research project complied with the recommendations from Resolution 466/12 of the National Health Council/Ministry of Health. After clarification, the participants signed the Informed Consent Form (ICF). The Human Research Ethics Committee approved this study under opinion 2.214.501 and CAAE 70890417.1.0000.5086.

RESULTS

The interviews showed that the study participants were three men and two women. The ages ranged from 42 to 57 years for men, and, among women, between 29 and 33 years. Among the participants, only one studied less than eight years, while the others had studied for 11 years. Regarding marital status, three participants were in a stable union, one was married and one, unmarried. This shows the predominance of males, corroborating a survey that showed that, in a large part of the world, men are more affected than women, due to issues related to gender, such as difficulty seeking the health service, late diagnosis and fear of losing their jobs because of the stigma of the disease (OLIVEIRA *et al.*, 2016). In relation to occupation/profession, one was a driver, one, a trader, one, a government employee, one unemployed and one, a freelance. This is also a relevant datum, once the pathology brings, as a negative repercussion, the decreased muscle strength, which can interfere with the working capacity of the affected person (SILVA *et al.*, 2014). Regarding the clinical form of the disease, only one interviewee could report receiving the diagnosis of dimorphic leprosy. The others did not know, because they argued that the professionals had not informed them. Regarding the type of reaction, only two people claimed to know: one reported type 2 and ant the other, types 1 and 2. The lack of information is remarkable in the scenario of leprosy and constitutes a barrier in coping with the disease, once it hinders its detection, delaying diagnosis, which ends up occurring in advanced stages of the disease, causing increased treatment duration and suffering of the affected person during this process. In a study carried out at Basic Health Units and polyclinics in the municipality of Palmas - TO, Brazil, the lack of information on leprosy was also an identified problem. This setting contributes to the continuity of the endless cycle of lack of knowledge of the patient about his/her disease, cooperating for the increased prejudice load (SOUZA *et al.*, 2013). During analysis of the participants' speeches, four thematic categories emerged: Changes in the life of a person affected by leprosy with leprosy reaction; The stigma of the disease and its impacts on the routine of the leprosy bearer with leprosy reaction; The family context in the life of a person affected by leprosy with leprosy reaction: support or exclusion basis; The everyday life of the leprosy bearer with leprosy reactions and his/her relations in the work environment.

DISCUSSION

Changes in the life of a person affected by leprosy with leprosy reaction: This first category is composed of units of analysis that refer to the weight of the changes brought by leprosy in various segments of their lives, from diagnosis,

covering treatment, to the cure of the disease or the appearance of reactions and how these transformations interfere in the routine.

“(…) it has changed, we feel different, I used to be vainer, and I’m not anymore (….) we get weird (laughter), awe get ugly” (E2F29).

The changes in the body of the person affected by leprosy are inherent to the disease and cause profound impact on self-image, often leading them to isolate themselves by fearing of what others will think and especially by fearing rejection. Leprosy is a disease that carries the idea of “ugly” (MONTE; PEREIRA, 2015). A study with the goal of evaluating the opinions of women with changes caused by leprosy on the changes in the body found that 96% of the people related a perfect body to the absence of changes in the skin aspect (PALMEIRA; FERREIRA, 2012). The changes in the life of the bearer of leprosy result from several factors: lack of knowledge, stigma, prejudice and fear of the disease. These conditions end up also affecting their social life leading to modifications in social behavior, isolation and low self-esteem both in relations with family as with friends and coworkers (CARRIJO; SILVA, 2014). “I have a grandson that used to play with me, but, many times, I do not play with him because I fear transmitting the disease (….)” (E4M57).

The fear of infecting other people leads the leprosy bearer with leprosy reactions to determine his/her own exclusion and isolation from society, making him/her stop participating in activities that belonged to his/her daily life routine. The prejudice arises not only from people outside the family environment. In most cases, the patient himself/herself draws up the prejudice, as can be seen in this study. The changes caused by the disease go beyond the social and psychological issues. Since it is an incapacitating disease, patients often report body aches and modification of their tasks of daily life, causing real changes in their lives, as well as the restriction of leisure and social practices. The limitation caused by the disease and the restriction of doing activities previously done create a feeling of inferiority and discourage patients, isolating them from their social context (BATISTA; PAULA, 2014).

“(…)I can’t be exposed to sunlight for too long, otherwise I develop a very strong allergic reaction... some foods I eat seem to worsen the pain in bone articulations (….)” (E1M42).

As a result, the patient feels forced to adapt to a new routine that should include frequent trips to the health service, receiving and taking the medication daily for at least six months, consultation with the physiotherapist, if necessary, and avoiding sunlight exposure (SÁ; PAZ, 2007). A study conducted with 40 people affected by leprosy showed that the changes resulting from the evolution of the disease cause important changes in the routine of patients, so that this condition does not pass through their lives unnoticed (MONTE; PEREIRA, 2015). The physical deformities caused by leprosy are another factor that interferes in the social and professional relations of the bearer, since it favors the maintenance of prejudice and decrease his/her work strength, causing psychological problems (LANA *et al.*, 2014). “(…) I have some sequela on both ears. I have little sensibility on my hands, which is almost null (….) it’s bad because we start to depend on others.” (E2F29).

On other occasions, the physical effects caused by leprosy are unnoticeable, because the person does not have a physical deformity, but feels weakness on hands and feet, which prevents him/her from performing daily tasks and labor activity (HAMESTER, 2016). Such difficulty appears in the report of participants and E3M53 and E5F33.

“(…) I feel on my finger, it’s not the same pertness I used to have before, the disease brought some weakness to my finger, and other two fingers get strange when I hit something, when I hit something with my elbow I feel a shock that hurts so much, like an electrical shock.” (E3M53). “(…) my right arm is weaker and now I’m realizing my left foot is getting weaker too, my little finger has no sensibility (….)and the blotches on other body parts got...numb.”(E5F33). Living under the judgment of this disease becomes, in every new negative discovery experienced by the bearer, a burden hard to bear. The once natural routine of joys and difficulties gives place to the disease, imposing greater challenges and a radical change in the life style. In short, the participants reveal, through their speech, the difficulty of living with leprosy and leprosy reactions, because the prejudice, social isolation and the impediment to perform the tasks of daily life are part of their struggles.

The stigma of the disease and its impacts on the routine of the leprosy bearer with leprosy reaction: The stigma and discrimination are closely associated with the leprosy throughout the history of civilization. The pains and physical sequelae cause radical changes in the everyday life of the patient, affecting his/her social and personal lives. Every day, the person affected by leprosy has to face prejudice, which hinders his/her healing and recovery (HAMESTER, 2016).

“(…) firstly, prejudice is what most impact us, because many people have no information, so they think - ‘Ah’she has this disease, I cannot live with it, I won’t hug her, I’m not doing anything.”(E5F33).

“(…) people told me I couldn’t stay with other people because I could transmit it (….) they told me I should retire because it is a transmissible disease.” (E3M53).

In the past, the treatment for the disease consisted of separating the sick person from society and putting him/her in colony hospitals. This practice served as support for the prejudice and stigma as we see currently: patients and their families marked, dead from a social point of view (SILVA *et al.*, 2013). Concomitant to the whole burden of suffering caused by leprosy are reaction pictures that exacerbate the initial symptoms of the disease and, thus, potentiate the sadness of the bearer, making them hide the marks of leprosy behind new webs of lies created in order to protect themselves from discrimination, since the reactions reveal the disease (SILVEIRA *et al.*, 2014). The fear of being discovered torments the sick person and causes changes in his/her routine, and the patient no longer attends places normally visited before. Some avoid talking about the disease, because they think that the less they verbalize it, the less will be the suffering resulting from social segregation (SÁ; PAZ, 2007). It is what we can perceive through the report of participants E1M42 and E5F33:

“(…) the fear of interacting more with people, of being together with them, afraid of people’s discrimination indeed (…) I stayed more at home, and almost depressed, because I stayed quiet, when not crying in my room.”(E1M42)

“(…)in my building, nobody knows about it, I avoid talking about it, I tell them I have allergies, thank God they believe.”(E5F33)

“(…) I lied, I used to say it was a mild allergy, I didn’t speak the truth.”(E2F29)

In the anguished attempt to try to hide the disease itself and leprosy reactions, the lie becomes part of the bearer’s routine, because the fear of being discovered and rejected causes a psychological torture. The difficulties faced by the patient generate a state of constant sadness, modifying his/her behavior toward society. This finding is consistent with a study conducted at prisons with seven patients, which showed that hiding the disease from the people of the social surroundings also constituted a form of preserving the patient from prejudice. The bearer avoids social interaction for feeling shame (SILVA *et al.*, 2014). The prejudice of patients themselves in relation to the leprosy makes them a victim of their own rejection, because they cannot accept themselves as bearer of the disease, as can be seen in the speeches of participants E2F29 and E4M57:

“(…)I had prejudice against myself because I thought it was a rocket science and had no cure (…)”(E2F29)

“(…) in my house, at its diagnosis, I sought to put my things away.”(E4M57)

A study conducted in Brazil showed a behavior similar to that of E4M57, in which one participant, due to lack of knowledge about how the disease infection occurs, sought to separate materials of collective use, such as dishes and cutlery in order to prevent the transmission to other people (SILVA, 2015). The historic social segregation and disabilities caused by leprosy bring to mind the idea of social death. The discrimination and abandonment cause profound marks on the daily life of patients and are common, since many of them are unaware of how leprosy really happens (NAKAE, HAMESTER, 2002; 2016).

“(…) how can I say it, knowing what people think about you and this disease showed me who people really are, my real friends (…)”(E5F33). The distancing of people once close to the sick person along the disease evolution is a common report among patients and causes deep sadness. This feeling can also be identified in the following report:

“I felt sad about the disease, some people distanced from me, I thought I couldn’t make it, I’d cry forever (…) those so-called friends haven’t spoken to me ever since (…)”(E2F29). The rejection directed to the bearer of leprosy persists because of the lack of understanding of people about the disease, transmission, treatment and cure. The stigma created in antiquity and the exclusion suffered by patients when hospitalized in colonies, separating them from their social interaction, also contributed to increase the impact of the disease on the patient (CID *et al.*, 2012). One of the statements of participant E2F29 shows that the prejudice can also arise from the healthcare team itself:

“(…) the doctor treated me totally differently, when I got into his office, he treated me differently, when he asked me

what kind of disease I had, and I told him it was leprosy, he backed off, using hand sanitizer and, I mean, I came back sad, but thank God I got over it (…)”(E2F29)

We realize that, despite the wide dissemination about the disease, forms of transmission and treatment, a large part of the population remains in ignorance, strengthening the stigma that permeates leprosy. This speaks corroborates the findings of a survey, in which one of the physicians who saw the patients in the health institution behaved doubtfully during the appointments, avoiding touching the patients, examining them at distance, prescribing and pushing the prescription for patients with the aid of an instrument (BITTENCOURT *et al.*, 2010). This stigma that accompanies leprosy is a recurrent factor in the speeches of the participants, but was not experienced by all of them:

“(…) not that much because she did not show it to me (…)
prejudice was not common to me, because few people know about it, because I don’t have any blotch.”(E4M57)

This report was unique, in which the interviewee does not report experiencing prejudice in his social environment. However, this was only possible, according to him, because few people knew about his health condition. Thus, this shows that secrecy is a common practice among patients. A study showed similar behavior, in which most interviewees revealed having not passed through situations of prejudice. Nevertheless, the majority also omitted the diagnosis from other people, hiding their condition from the social group around them (LOURES *et al.*, 2016). In this way, the patient’s difficulty to understand and accept the disease becomes evident, since the person hides this fact for fear of facing personal and professional repercussions he/she may suffer.

The family context in the life of a person affected by leprosy with leprosy reaction: support or exclusion basis:

The bearer of leprosy often adopts a posture of remoteness or social isolation, restriction of closeness to the people nearby and family members who are often not prepared for the emotional impact that the disease can generate (SOUZA; MARTINS, 2018). Family members are expected to offer affection, comprehension and patient care, protecting him/her from a more serious repercussion on the emotional aspect. This family support, as well as the health professional, is essential for the individual’s recovery and contributes to adherence to treatment and self-care (MARINHO *et al.*, 2014). The analysis units that comprise this category showed observing with unanimity that all participants informed their relatives about their disease and received support:

“(…) not at home, they accepted breezily (…)

(…) the only people who didn’t distance from me were my family (…)

they supported me very well.”(E2F29)
“You know, I told them (…)

there was no problem at home, changing clothes, sleeping in separate beds, nothing (…)”(E3M53)

“They all know, all my relatives know I have this disease.”(E4M57). “My family knows, they act normally as if I had nothing, they treat me well, thank God, (…)

they ask me if I’m doing fine (…)”(E5F33). The family is an important support in coping with the disease, since it helps the affected person accept his/her condition, and not feeling isolated. In

this study, most of the research participants received support from their families (LOURES *et al.*, 2016).

Nonetheless, there was a report of a family member's difficulty to cope in an isolated manner that presented an unexpected reaction, as we can see in the speech of E5F33:

In a study conducted with three groups of residents in southeast Brazil, considered in a situation of high endemicity for leprosy, the aforementioned situation could be observed and directly relates to the fear of transmission through the use of household utensils and produces social isolation (RAMOS, 2017). This study underscores that health education to patients' families is of extremely importance in order to achieve success in the treatment and reinstate this person in society with a healthy mind and body (SOUZA; MARTINS, 2018). The participant E2F29 still emphasized that, during the course of her illness, she realized that her family united to help her overcome this difficult phase.

"(...) my family got closer, we weren't close, but after I got pregnant and this reaction appeared, my family got closer, my niece and I used to argue all the time, we spent a time apart, and now she's right here by my side (...)"(E2F29)

In the family context of E2F29, the once existing differences were overcome and there was a greater union of her relatives who were willing to accompany and assist in the treatment. A study identified similar behavior, which performed a bibliographic review about the subject (SANTOS; BERTELLI, 2017). One of the interviewees mentioned that, when telling his family about the disease, many of them did not know exactly what it was:

"(...) I told them, but they had no idea about what the disease was, but I told them and they understood it normally."(E3M53).

Despite this initial lack of knowledge due to lack of information about the disease, E3M53 reported explaining to his family later and receiving full support from them. Information about leprosy must be transmitted correctly by health professionals, especially to the families involved in this process (SOUZA; MARTINS, 2018).

The everyday life of the leprosy bearer with leprosy reactions and his/her relations in the work environment:

Leprosy is an ancient disease, classified as neglected, which exemplifies that one's life style can reflect on this person's health-disease process. In the work environment, one can observe how social relations and the reactions of the society about being sick occur (GONÇALVES *et al.*, 2018). The work represents historically the main means of family living and of meeting survival needs. Moreover, it constitutes an agent of social integration and reason of self-accomplishment in the life of society in general (BATISTA; PAULA, 2014). Leprosy is a disturbing event in the life of the affected person, because, in addition to changing his/her self-image, the fraternal ties and social life, still causes devastating repercussions in working relations, as we can see in the speech of participant E1M42:

"(...) my ex-bosses (...) found a way for me to retire... so that I could stay away from their two daughters I practically raised."(E1M42).

A study conducted with 94 patients undergoing treatment at health units of a Brazilian municipality also revealed the burden of human suffering resulting from exclusion and discrimination experienced in the workplace (GARBIN *et al.*, 2015). The prejudice experienced in this context are not uncommon and were reported by other respondents:

"(...) my coworker told me to put my clothes away from his, because I could transmit the disease to him, (...) and, because of it, he told me to leave the activity I had with him."(E3M53)

"(...)at work, I suffered prejudice from only one person (...) I work at the financial sector and she is cashier, she couldn't have lunch with me, and every time she had lunch after me, she put a bag over the chair because she thought she would get infected just because she sat on the same chair I did (...)"(E5F33).

Even suffering this type of reaction from one of his coworkers, the participant E5F33 reported receiving full support from her bosses:

"Their first reaction was giving me support, thank God, full support, they had no prejudice against me, they supported me, telling me: -Look you'll get over it, let's treat it, seek information. They have supported me ever since, always hugging me, supporting me."(E5F33). This acceptance by employers is extremely important, since it facilitates the process of treatment and somehow makes patients feel welcomed and understood. A study also observed this behavior, in which the participants informed about the disease to their bosses and received their support (SILVEIRA *et al.*, 2014). Another participant stated, during the interviews, not commenting about his disease in the work environment:

"No, they don't know (...) no one has ever asked me, so I won't say anything about something I will never transmit (...)"(E4M57)

At work, the impact of leprosy relates to the fact that patients represent a danger to their coworkers. In this scenario, people affected are prone to unemployment, especially when the disease becomes public in the working environment (GONÇALVES *et al.*, 2018). Secrecy is an alternative often more feasible to the affected person, because he/she prefers not suffering the probable consequences of disclosing the disease in his/her workplace. As already seen, the leprosy directly affects the everyday life of the affected person due to the constant threat of prejudice, isolation, physical disabilities that inevitably cause negative repercussions in the social environment surrounding the bearer (SILVA *et al.*, 2014). A limitation of the present study was carrying out only two meetings with each participant, not allowing strengthening the bond formed, which may have interfered with the quality of the answers. In addition, some invited patients refused to participate in the study, even after the clarification about its objectives and the guarantee of confidentiality of the identity. These limitations open possibilities for future investigations.

FINAL THOUGHTS

This study sought to reveal the contexts and experiences surrounding the person affected by leprosy with leprosy reactions by seeking to understand what impacts the disease, injuries and consequent disabilities most affect his/her routine.

The present study provided knowledge about the perceptions of prejudice experienced by individuals, a fact that has been lasting for generations in relation to the person with leprosy, and especially when the bearer presents leprosy reaction. The patient's lack of knowledge, which sometimes hinders the healing process and increases the suffering, was also a behavior observed in this study. The less knowledge the patient has, the greater the likelihood of the emergence of incapacity, which makes daily tasks more difficult and often ends up taking the affected person from his/her occupations. The development of this survey showed that leprosy is still a very difficult issue to address, considering its history of prejudice and isolation of the affected person. The changes generated in the body by the process of illness cause several changes in the everyday life of the person, which was also observed in the participants' speeches. The physical deformities and the leprosy reaction lesions make the patient a prisoner of his/her own home, preventing him/her from leaving for fear of others' reactions.

The episodes of reaction are responsible for the worsening of old lesions caused by leprosy or emergence of new, increasing the likelihood of developing physical disabilities. Some participants reported loss of strength in some limbs, numbness where there used to be blotches and in upper and lower limbs, factors that contributed to the modification of their routines. All participants somehow felt the social impacts of leprosy reaction, whether from their family, at work or in another environment. Some were mild, while others were more intense. The statements showed a daily burden of suffering experienced by the bearer of leprosy with leprosy reactions and his/her family, which is entangled in this web of sadness and loneliness. In this sense, health education work is necessary in order to banish the prejudice and stigmatization of affected people, because, if there is no awareness, leprosy will continue spreading and bringing the bearer more suffering generated by fear of discrimination. The nurse, in this context, plays a fundamental role, for being responsible for clarifying the misinformation about the disease and its complications, for forwarding the bearer to a correct and effective treatment, in addition to emotional and instrumental support to the person with leprosy and leprosy reactions, encouraging him/her regarding the occurrence of reactions that may arise throughout the treatment.

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