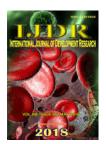


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KNOWLEDGE OF USERS AND PROFESSIONALS OF PRIMARY HEALTH CARE ABOUT LEPROSY

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ABSTRACT

This study aimed to describe the knowledge of users and health professionals in the context of Primary Health Care (PHC) on leprosy. This is an exploratory-descriptive research, under a qualitative approach, developed from September 2014 to September 2015, in Sobral, Ceará, Brazil. The study subjects were users of PHC in health services, with or without leprosy, and midlevel health professionals, in the categories of auxiliary and nursing technicians and community health agents. Information was collected through semi-structured interviews. The users, although their speeches presented divergences, many manifested to know the form of transmission, treatment, where to seek care, consequences and possibilities of cure of leprosy, but others, are not aware of this structure to cope with the disease. All though acknowledging access to diagnosis, treatment and cure, prejudice was emphasized by participants, considering it persistent in society. The participants stated that the knowledge gained was based on the guidance of PHC professionals, friends, family and the media. The main changes in life after diagnosis were related to drug treatment, which interfered with daily activities. It is important to highlight the family support in this course. The professionals consider that training is necessary and that the service remains active, providing a quality service. Admitting leprosy as a public health problem, investing in information and discussing / negotiating ways to address it, supports the possibility of reducing the burden of disease and discrimination of patients.

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INTRODUCTION

Leprosy is one of the oldest diseases of mankind - there are records in historical writings, being known for its long relationship of incurable evil and divine punishment. Caused by Mycobacterium leprae, which is an agent with high infectivity and low pathogenicity, that is, it has a capacity to infect many subjects, but few become ill. At the present time, treatment and cure is available, being in the list of infectious diseases of chronic character, with involvement of skin and peripheral nerves, being of slow evolution.

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After millennia, even with the scientific discoveries, treatment, cure and terminological change of the disease, subjects with a diagnosis of leprosy still suffer from prejudice and discrimination caused by the lack of knowledge and popular imagery related to the disease in the past (Moreira, 2010; Ministry of Health, 2010a). According to World Health Organization (WHO, 2013) data, in the world, in 2013, 215,656 new cases of leprosy were identified, of which 13,289 were Grade 2 disability, reflecting the poor capacity of the health services to detect the disease early. Of all new cases, 9.2% were in children, which also indicates the continuity of the active transmission of the disease in the communities. Brazil now ranks second in number of diagnosed cases, second only to India (Ministry of Health, 2010a).

The North, Northeast and Center-West regions are considered more endemic, with areas of important transmission maintenance (Ministry of Health, 2015). In 2014, the coefficient of prevalence of leprosy in Brazil was 1.27 cases / 10 thousand inhabitants, representing a reduction of 25% in relation to the value of the coefficient of the year 2004, which was 1.71 cases / 10 thousand inhabitants (Ministry of Health, 2013). In the State of Ceará, in 2015, 1,743 new cases were reported, accounting for a detection rate of 20.25 cases / 100,000 inhabitants (Ceará, 2014). Sobral, municipality of the Northwest region of Ceará, presents a history of endemicity of leprosy. In 2013, according to the local data of the National System of Notifiable Diseases (SINAN), this municipality achieved a detection rate of 44 cases / 100,000 inhabitants, which, according to the parameters of the Ministry of Health (2010b), is characterized as hyperendemic and priority in the development of disease control and elimination actions. For this reason, leprosy, in addition to its magnitude, must also be thought for its transcendence, since which brings serious physical, emotional and social repercussions, especially if it is not diagnosed and treated early. However, Primary Health Care (PAH), as a coordinator of the Health Care Network (Ministry of Health, 2011), can play an important role in leprosy control actions because the treatment / follow-up happens in the territory where the sick person lives, an important strategy for the elimination of the disease in Brazil (Aranteset al., 2010), a decentralization that requires training of health professionals, freedom of work and commitment (Rios, 2003). This study aimed to describe the knowledge of users and health professionals in the context of PHC on leprosy.

MATERIALS AND METHODS

Exploratory-descriptive research, under a qualitative approach, developed during the period from September 2014 to September 2015, in Sobral, Ceará, Brazil. Studies of a qualitative nature seek to understand human phenomena as part of social reality (Minayo, 2016). The municipality of Sobral / Ceará has an estimated population of 201,756 inhabitants by 2015, highlighting itself in the region as a reference point for services of medium and high complexity in public health, as well as for its with approximately 100% of the population covered by the 64 Family Health Strategy (FHP) teams at the 33 Family Health Centers (CSF). The subjects of the study are users of PHC health services, with or without leprosy, and mid-level health professionals, nursing assistants and technicians. The subjects chosen were those belonging to the visited territory as users and health professionals. In each CSF, 15 interviews were conducted, five with each category described (UP, UNP and PS), all of which expressed their desire to remain in the research, authorizing the transcription of their speeches. The sites of approach to the subjects of the research were in five CSF, of areas of high endemicity, being: CSF TerrenosNovos, CSF Padre Palhano, CSF Coelce, CSF Expectativa and CSF Alto da Brasília, all located in peripheral districts of Sobral. For the collection of the information, semi-structured interviews were carried out, and their statements were recorded after authorization of the subjects, with subsequent transcription. The analysis technique was based on the theoretical framework proposed by Minayo (2016), based on the technique of content analysis in the thematic modality, which comprises the type of technique most used for content analysis, consisting of operations of splitting the text into units (categories), according to analogue groupings, proposing a qualitative organization of information. After analyzing the content, three thematic categories emerged: axis I: knowledge about leprosy and sources of information about the disease; axis II: The care that must be taken with the disease and its consequences; and Axis III: Knowledge about access to the treatment of leprosy cases.

This research is a cut-off of the leprosy project in children under 15 years old: use of social networks and genetic tools in the study of the transmission of Mycobacterium leprae, and its accomplishment guaranteed by the Ethics and Research Committee of the Federal University of Ceará, CAAE: 17919613.6.0000.5054 e report number: 624.393. As In order to preserve the anonymity of the study subjects, the following denominations were used: User Carrier (UP1 to UP6), Non-Carrier User (UNP1 to UNP9) and Health Professionals (PS1 to PS6).

RESULTS AND DISCUSSION

The FHS aims at reorganizing PHC in the country, in accordance with the provisions of the Unified Health System (SUS), playing a central role in ensuring access to the population and quality health care. The absence of this contributes to delaying the diagnosis and dissemination of diseases, as well as increasing the number of physical disabilities that may be irreversible in the late diagnosis (Pereira *et al.*, 2008). Next, the three thematic categories that emerged from the subjects' speeches are described.

Knowledge about leprosy and sources of information about the disease

The main route of transmission is the entry of Micobacteriumleprae through the upper airways, and cases classified as multibacillary leprosy transmit the disease to healthy subjects (Ministry of Health, 2010). In this sense, there is a similar idea among the research subjects that leprosy is an infectious disease and is transmitted from one person to another by some form of physical contact, according to the following statements:

Of infectious-contagious disease I know is leprosy, tuberculosis, acute respiratory infection and diarrhea [...] as a catch, I say that it is caught by physical contact, by air transmission, sneezing, near speech and close contact. (UP 6).

Transmission is by droplets [...] the healthy person comes in contact with the person who is in the active phase of the disease, lives in the same environment, is dimly lit, humid and well-populated and makes that person more likely of contracting the disease. (PS 3).

The form of transmission of leprosy is still not fully understood, although it is attributed to the intimate direct contact with a case of bacilliferous disease and without treatment, whether familiar, at work, at school, among others. In this sense, examination of the contacts of subjects diagnosed with leprosy (multibacillary - MB or paucibacillary - PB) is one of the most important strategies to interrupt the transmission chain. The difficulty in understanding or lacking communication channels that can clarify the population about leprosy can be perceived, also, in the following speech:

That I know this one of the blotches right ... and just ... no, I do not know how to handle it and neither the symptoms ... I only know that some spots appear ... right from what I saw, the person feels a numbness, the person if it burns and does not feel, that's it ... and what I know is what I see at the health clinic. (UNP 5).

A user and a healthcare professional identify the importance of the examination of the contacts as a control measure of leprosy and that, with the beginning of treatment, the bacilliferous patient stops transmitting the disease:

In the guidelines at the post they said that mine was no longer for anyone, since it was already in treatment, from there they examined everything home world and everyone took the vaccine [BCG], [...] only I got the disease. (UP 4).

Initially, [...] one should seek out the health unit and see if it is not another blemish, to actually give the diagnosis of leprosy and subsequently have to treat. Pick up all the communicators, the household contacts of the case, the people with whom the patient has had more contact in the last few months to actually do the tests and evaluations, and make sure they have or have not contracted leprosy. Then start treatment if it is positive. (PS3).

When the leprosy patient starts chemotherapy, he stops transmitting the disease, because the first doses of medication reduce the infectious potential of M. leprae, thus eliminating the source of infection (Ministry of Health, 2010b); therefore adherence to treatment and follow-up by the health service are as important in the control and possible elimination of the disease, which can be considered as a public health problem. In the face of the CSF practices, what is perceived is that the identification and the examination of the contacts are the pillars for the effective control of leprosy, knowing also that the early diagnosis allows the adoption of the measures, as well as indicate immediate therapeutics in each case, as recommended by the Ministry of Health (Ministry of Health, 2010b). The standard setting guidelines for surveillance, care and control of leprosy is that all contacts and / or contacts of new cases of leprosy should be evaluated, and administration of the BCG vaccine is required depending on the vaccine history of each case. As to the diagnosis of leprosy, this is essentially clinical and epidemiological, performed through the analysis of the history and living conditions of each dermatological symptom, dermatoneurological examination to identify lesions or areas of the skin with changes in sensitivity and / or impairment of nerves peripheral neuropathy, as well as neural impairment, which present no cutaneous lesions, which are the most complex to confirm the diagnosis(Ministry of Health, 2010a). These clinical signs were also recognized by the study subjects:

They are usually dormant patches that do not itch, do not ache, numbness, tingling in the hands and feet, and shocks to the elbows and calcaneus [...] people confuse a lot with acne and other diseases. Another case is the nerves, because when they are atrophied they become more visible, in the case when leprosy is in the nerves [...], which are the most serious cases. (UP6).

Today, as I am patient and I am going through this problem, then they have clarified me about the disease. People who do not have a qualification, [...] do not understand the extent of such a disease [...]. About the

symptoms, I noticed spots on the body, and they were spreading over time. (UP2).

Thus, campaigns to clarify the population and actively search for new cases of leprosy in the community, the distribution of posters and folders on leprosy, and the dissemination of messages on radio and television stations are carried out in a timely manner, however. as they make information more accessible, increasing the chances of detection and early diagnosis:

Some information I heard was through a TV channel right here in Ceará. (UP2).

Yes, my son arrived with a file that they gave to the school where he had an engraving and some questions for us to answer about leprosy. (UP3). I heard about at the health center. (UNP 5).

Therefore, permanent actions that inform the community are fundamental for the effective control of the disease.

The care that must be taken with the disease and its consequences

The combination of functional limitation, social prejudice and human suffering that accompanies leprosy explains why it is a more feared disease than others, even if we consider terminal diseases without prognosis. In the view of a carrier, leprosy causes limitations in its daily life, mainly due to the care that must be taken to minimize the effects of multidrug therapy, as well as the reactions of the disease and treatment:

In fact, I know there are several cautions, like depriving yourself of the hot sun, avoiding [alcoholic] drink and some meals. But what really disturbs me is the sun, I have to work to fulfill my responsibilities; [...] but I am cautious, I always use sunscreen, I also use mineral oil that the nurse has passed [...]. I try to work at times when the sun is warmer [...]. The consequences are numbness, a tiredness, the indisposition at the beginning of the treatment, I believe because of the drugs that are strong. (UP 2).

Person has to take care of and treat the disease properly, [...] not to transmit to other people [...]. And it also has the consequences if you do not get the treatment right. (UP 5).

The main clinical manifestations of the disease are those related to peripheral neurological impairment, which results in a great potential to cause physical incapacities, and can develop into deformities (Ministry of Health, 2010a). In several contexts, the negative social image of leprosy affects evaluation and management, as well as effective measures for prevention, treatment and, consequently, the breakdown of the community transmission chain, a situation that can be understood in the following speech:

The worst consequence for me was prejudice! Because I knew a little about the disease, because I was recently working in the Family Health Program as a community health agent, I discovered that I had just gotten in the area of my coverage ... but the nurse and my family helped me overcome [...]. It was very difficult! People discriminated against you, so I did not assume it was leprosy! Today I would speak openly, but ten years ago it was not easy (UP 6).

Although the cure for leprosy has already been achieved, prejudice is historical and biblical, permeating the life of the patient and his family to remain in their social environment.

Knowledge about access to care for cases of leprosy

The access of families, individuals and communities to actions and health services runs through the current health care model, the universalization of health policies and the installed capacity of the local health care network, as well as qualified health professionals, compromised and sensitive to the performance of leprosy control actions, with the availability of instruments to perform the dermatoneurological examination, Hansen smear microscopy, among others that corroborate the control of the disease. Nursing professionals play a key role in the process of leprosy work, since they are responsible for planning, implementing care actions, controlling patients and contacts, and performing first care for leprosy patients. instigates the development of a qualified hearing for the success of the treatment:

I went to the health clinic, was attended to by the nurse, then she was tested with that tube of hot and cold water and was "trying". There were some that I felt less than other places know, she asked for tests and told me to return there with the result, and then I'm about to start treatment. (UP 5).

The training of professionals on leprosy is fundamental in obtaining and successfully controlling leprosy, especially in places where the endemicity of leprosy is high.

I looked for the nurse in my area at the time and she referred me to the reference point near Santa Casa, where MORHAN worked. There I did the exams and was diagnosed that I had leprosy. (UP 6).

In services where leprosy control actions were decentralized, we encountered difficulties on the part of professionals in defining the diagnosis of leprosy. This difficulty can be mitigated by the institution of permanent education processes addressing the subject and the provision of a referral service that gives the field of PHC guidance and transfer of experiences with the cases (Pereira *et al.*, 2008). Health professionals already understand the logic of the decentralization of leprosy actions in PHC, but are unaware of some internal workflows and processes of the municipality, explaining the limits of decentralization:

Look for treatment at the health clinic, or at the referral center. (UNP 9).

Yes, look for the staff at the nearest health facility. (PS 6). It starts in the PSF, now where it does, if it goes to the other place, I do not know [...] I know that it does an examination outside the PSF, but where it is, I cannot say [...]. But the medicines the person picks up in the HFS. (PS1).

Decentralization of control actions is one of the main strategies to eliminate leprosy, since it facilitates the population's access to diagnosis and treatment in the initial phase of the disease, as well as active contact search and educational actions, since have professionals who can perform such activities (Lanza and Lana, 2011).

Final considerations

In the report of some users of the service, it is evident that information about certain diseases is not clearly disclosed to the general population, reaffirming that in the vast majority, only those with the disease and the closest contacts, have more detailed information on the forms of contamination, pathophysiology, preventive measures and treatment of infectious diseases such as leprosy. In the study, it was important to recognize that information on leprosy is characterized as one of the reasons for seeking treatment, and prevention is essential in the struggle for its elimination as a public health problem. In the opinion of the users who had leprosy, after the diagnosis and the beginning of the treatment, they felt an improvement of the symptoms, but also experienced unpleasant feelings, either due to the prejudice or the treatment reactions, directly influencing the quality of life. In this sense, it is essential the support of health professionals to these subjects, paying full attention, as well as the support of the family. Health professionals feel a need for greater knowledge about the approach and clinical accuracy of leprosy for the development of control actions at the PHC / HFS. The main challenge for health managers in municipalities where leprosy is prevalent and difficult to control is the decentralization and implementation of PHC actions as a strategy to reorient the care model. However, this study made it possible for a modest portion of the population to express their knowledge about leprosy, essential to indicate that the broader their level of knowledge, the greater the chances of diagnosis, early treatment and cure, and the reduction of feelings of prejudices and uncertainties about the cure of leprosy, as well as the consequent breakdown of the transmission chain.

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