ABSTRACT
Objective: Investigating the knowledge of users of Primary Health Care about leprosy. Method: a cross-sectional, descriptive, exploratory and qualitative study with 55 participants at a Family Health Unit in the city of Campina Grande/PB/Brazil. Data were collected through interviews with structured script, transcribed verbatim, and treated in the light of Discourse Analysis, after project approval by the Research Ethics Committee, CAAE No. 0613.0.133.000-10. Results: after data analysis it identified three categories: << Knowledge about leprosy and Sources of Information >>, << Knowledge about Transmission and Preventive Measures >> and << Association of Leprosy to Stigma >>. Conclusion: leprosy is related to values and social practices, with significant knowledge deficit by the subjects, concerning transferability, symptoms and prevention. This fact demands engagement with health education of the population, making an active and an effective process, reverberating in the early diagnosis, treatment and social stigma. Descriptors: Leprosy; Knowledge; Primary Health Care.

RESUMO

RESUMEN
Objetivo: investigar el conocimiento de los usuarios de Atención Primaria de la Salud acerca de la lepra. Método: un estudio transversal, descriptivo, exploratorio y cualitativo con 55 participantes en una Unidad de Salud de la Familia en la ciudad de Campina Grande/PB/Brazil. Los datos fueron recolectados a través de entrevistas con guión estructurado, transcritas textualmente, tratadas a la luz del análisis del discurso, después de la aprobación del proyecto por el Comité de Ética de la Investigación, CAAE No. 0613.0.133.000-10. Resultados: tras el análisis de datos se identificaron tres categorías: << Conocimiento acerca de Hanseníase y Fuentes de Información >>, << Conocimiento acerca de la Transmisión y de las Medidas Preventivas >> y << Asociación de la Lepra al Estigma >>. Conclusión: la lepra está relacionada con los valores y las prácticas sociales, con significativo déficit de conocimiento por parte de las personas acerca de la transmisión, a los síntomas y a la prevención. Este hecho exige el compromiso con la educación sanitaria de la población, haciéndose el proceso activo y eficaz, reverberando en el diagnóstico temprano, el tratamiento y el estigma social. Descriptores: Lepra; Conocimiento; Atención Primaria de Salud.
INTRODUCTION

Leprosy is an old public health problem in Brazil and it is still one of the most important challenges to health authorities. Besides aggravating inherent to any disease of socioeconomic and cultural background, it is punctuated by the psychological impact generated by deformities and physical disabilities resulting from illness, for which conditions the patient to live experiences of stigma and social exclusion.¹

The epidemiology of leprosy in the world still remains with gaps and puzzles, which suggests the adoption of more effective measures.² Although the prevalence has been much reduced through shortened diagnostic and treatment programs, the detection rate of new cases remains high in many parts of the world, including in Brazil, preventing it from reaching the target set of 1/10.000 inhabitants, a parameter which the disease is considered eliminated.³

Brazil is considered the 2º country in the world in leprosy cases, and gathers more than 80% of cases in the Americas, being classified as an only endemic country in the continent.³ The distribution of the disease is not homogeneous in Brazil, since it presents very high rates in the North, Midwest and Northeast regions, comparing to states in the South and Southeast. This heterogeneity in the distribution of leprosy, articulated to regional differences in cultural, social and economic aspects, indicates the need for formulating and implementing appropriate action plans to each region, in each historical and political moment.⁴

The National Leprosy Control Program (PNCH) establishes operational guidelines for performing different actions, coordinated and integrated, with an emphasis on horizontality and decentralization that are organized around structural axes such as epidemiological surveillance; comprehensive care; communication, education and research.⁵

The promotion of dissemination media campaigns developed by PNCH happens since the 1980s, with the goal of providing to population knowledge about the disease.⁶ Educational, social and pedagogical strategies are also developed allowing the construction and reconstruction of knowledge through a participatory teaching-learning, dialogical and problematizing process.⁷

Partnerships with social technologies strengthen the promotion and prevention essential to leprosy control. In this sense the Federal University of Campina Grande (UFGC), the State University of Paraíba (UEPB), in partnership with the Municipal Health Secretariat of Campina Grande, seek to developing initiatives to control the disease through education-service-community with insertion of Education Program through Work (PET) in Health Surveillance in primary care services.

The PET-Surveillance aims to encouraging the formation of groups learning tutorial in strategic areas for the Unified Health System (SUS). The proposal is to developing the process of teaching-learning in a participatory manner, with the central axis in the daily work of health services, with the use of the tools of research and evaluation in health knowledge construction.⁸ Thus, it is necessary grasping the reality that from the needs found it is possible to planning and performing actions in the community through communication and education tools.

It is believed that the findings of the study may contribute relevant information for the guidance of managers, program managers and service professionals, in order to plan actions and making decisions appropriate to their reality thereby contributing to health services.

OBJECTIVE

- Investigating the knowledge that Primary Health Care users have about leprosy.

METHOD

A cross-sectional, descriptive, exploratory qualitative study conducted in the city of Campina Grande, located in geoenvironmental unit of Borborema Plateau, arid Paraíba mesoregion. It has a population of 385.276 inhabitants and covers an area of 621 km². It is a priority city by the Ministry of Health for action on leprosy control.

It was selected as the research site a Family Basic Health Unit (UBSF) that serves a population of 6.437 families with coverage of four neighborhoods of the municipality. This choice is justified by this being the area considered hyperendemic in the county, with a prevalence of 4,97 cases per 10.000 inhabitants.

The study population was composed of registered users in that UBSF. The sample was non-probabilistic, constituted by accessibility. There were considered as inclusion criteria: being over 18 and present in the waiting room on the days set for completion of data collection (spontaneous demand). The 55 participants were informed of the total freedom to participate or not and give up on
any of the stages of the research, signing, if so, the Instrument of Consent.

Data were collected between March and June 2011 through semi-structured forms. Before collecting, the instrument was submitted to the pretest to remedy inadequacies and not understood issues, improving the clarity and objectivity of the questions, in order to reducing the possibility of bias.

The answers to the questions were transcribed verbatim in the text, used to identify the letter U (user) and numbering from 1 to 55 The reports were analyzed by means of discourse analysis, based on the theme, which is defined as the discovery of groups of meaning and constitute a communication about the frequency or the presence of some significance to the object being analyzed.

It was performed the pre-analysis of data by reading of the entire material; then the information was organized to making it operational and systematized to conducting a precise scheme for development of other stages. Ultimately, exploitation of the material, allowing for exhaustive reading and identifying the outline of the emerging classes was performed. These data were aggregated according to the similarities and thereafter classified into empirical categories and analyzed by means of inferences and interpretations provided the theoretical framework for or suggested reading material.

With regard to ethical aspects, the study was submitted to the State University of Paraíba Research Ethics Committee, under CAAE No. 0613.0.133.000-10. At the same time it was requested by letter the permit to the coordination of Primary Care of the Municipal Health Secretariat of Campina Grande/SMS/CG.

RESULTS AND DISCUSSION

The research involved 55 persons, 41 (74,5%) women. The sample showed age extremes: ages 18-74 years old have been reported, with overall average of 37.63 years old. Predominated up individuals aged between 18-30 years old (49,1%), married or in a stable relationship (56,4%) with complete primary education (32,7%), brown (52,7%), with “home” occupation (41,8%) and income of up to one (1) minimum wage (60,0%).

The units of meaning that emerged from the analysis were << Knowledge about leprosy and Sources of Information >>, << Knowledge about Hansen’s disease Transmission and Preventive Measures >> and << Association of Leprosy to Stigma >>.

- Knowledge about leprosy and Sources of Information

Being one of the oldest diseases, it asked users “Do you know what leprosy is?” Two of them associated Hansen’s disease to its origins, referring to the term leprosy.

[...I think is leprosy, has several types of lumps, swelling. (U53)]

I know it’s a disease that is on the skin, equal to the leprosy of yesteryear, only now have treatment. (U25)

The term leprosy, even today, carries a subjectively related to segregation and prejudice connotation. The use of this term was outlawed in 1976 in the documents of the Ministry of Health through Ordinance No. 65 and the direct administration in 1995, through Law No. 9010, whose purpose was to minimizing the discretionary cultural problem and bring significant results in the elimination of stigma.1,10

“Leprosy”, despite advances, continues to be remembered by the community as a disease of suffering at the expense of “Hansen’s disease”, which appears as a subdued and relatively unknown disease, as evidenced by the following speeches:11-12

I know what it’s like. I read a lot, but now fled the mind! (U9)

Is a kind of itch that passes to the blood. (U21)

It can be transmitted through allergy [...]. Depends on the profession that the person has and if you have contact with dust. (U33)

I think it’s in the blood, but leaves some ugly blotches on skin. (U22)

Are red spots, little lumps that we don’t feel. (U11)

Participants frequently referred in isolation to associated signs and symptoms not related to the disease etiological factors. Importantly, at the time of the interviews, such elucidations were loaded with a strong sense of disagreement over the disease.

The population erroneously lists the patches on the skin to differential diagnosis of leprosy, such as tinea versicolor, vitiligo and tinea of the body, and end up using inefficient devices, based on the popular wisdom, to treat the disease, such as medicinal herbs and faith healing prayer. As a result there is delay in diagnosis and treatment which undoubtedly implies a larger number of multibacillary demonstratings and injuries resulting from the evolution of the disease.13

The spatial distribution of the clinical forms of leprosy can be explained by unequal access to health services associated with lack of knowledge of the population, a result of the deficit of educational activities at
community level, making it necessary thus to knowledge dissemination and identification of signs and symptoms.13

In 83.6% of cases, the participants reported having obtained information about the disease, and 65.5% of these through television, radio or virtual media; 18.2% by health professionals; 7.3% from newspapers, magazines and pamphlets and 5.5% at school. In 9.1% of cases other people passed information.

Those who claimed to know what it was leprosy, the majority referred to the main symptoms and disabilities, evidencing that were reported at some time:

\[
[...] \text{it is that (illness) which burns, that we don't feel pain when burning with fire. (U5)}
\]

\[
\text{It's a disease that is on the skin, it doesn't hurt. It appears on television from time to time. (U13)}
\]

\[
\text{It is a disease that is on the skin, which loses the sensitivity in the place where is with spots and has treatment. (U28)}
\]

\[
\text{Are spots that if we pinch, don't feel and the person may lose fingers. (U32)}
\]

\[
\text{It is a disease that affects the nerves, with reddish spots, lump and reaches the muscles. (U55)}
\]

It can be seen that a major obstacle to elimination of the disease is ignorance. The elimination of leprosy is a priority of health managers in the three spheres of government, as agreed in the Pact for Health.14 Thus, actions and preventive, promotional and curative strategies, in order to expand the knowledge of the population, especially in relation to transmission, prevention and control are essential and inseparable factors of this process.15,16

- Knowledge about the transmissibility of leprosy and preventive measures

When asked how leprosy is transmitted, 33.3% reported that the most likely way of transmission was through contact with the skin of patients, 23.8% stated that leprosy was transmitted by air, 14.3% by water and contaminated food, 9.5% by cutlery and fomites, 9.5% by contaminated blood and syringes and 10.0% did not know.

It is noticed that some of the users have heard about the disease but do not know how to effectively acquire, its causes and ways of prevention. The leper itself is unaware of the disease.17

Leprosy is popularly conceived of as a disease that can be passed by a simple skin contact, which is transmitted while the lesion is present. In fact, the lack of knowledge about the transmission of disease favors the transmission, since it occurs through the upper airways of a patient without treatment Multibacillary. It is noteworthy that soon after starting treatment there is a load reduction bacillary with decreased transmissibility. In this sense, it is questioned “do you think we can prevent leprosy?” There were doubts about the concepts of prevention and treatment, which could be perceived in several speeches:

- With treatment there's a cure. Everyone avoids with treatment. (U5)
- Yes. Consulting the doctor, taking medication and treatment. (U12)
- The person when is infected there's no help, only with treatment is that one avoids. (U30)

Treatment is essential to the patient so that it can heal itself. Treating the infection source stops transmitting. However, intensive dissemination of the signs and symptoms of the disease, stimulating demand for health services, maximizing the active search efforts of dermatological symptoms and immunization with BCG are key measures to endemic control.13

The concept of prevention is directly associated to the idea of transforming the individual promoter of health in the individual and collective levels. The aim is thus acting in the prophylactic field; with the premise contribute to quell speeches with passive and fatalistic tone senders to disease, such as:

- The person does not prevent disease. [...] I think that comes with the time. Only God that can help it! (U32)
- If I have to pick it up. Anyone looking for disease. (U7)
- It's a thing on the wind, which comes rolled. It's hard to avoid. (U9)
- When comes, you can't avoid. We're not far from bad thing. (U13)
- It comes in it even, equal to cancer, you can't prevent. The only disease you can prevent is AIDS. (U16)
- No! It appears casually, equals frog without the person asking, without the person knowing. (U29)

For the prevention of this disease being effective, it is necessary to develop a process of understanding the importance of cultural and environmental changes in the population. Only condone and participate in the changes that communities feel effectively sensitized.18 There must be understanding and acceptance in order to be paid the population in health promotion process.

It is necessary, then, to recognizing the people, understanding their way of dealing with leprosy, understand their habits and customs. Various meanings have been noted in speeches from those in which there was an absolute lack of knowledge about the
prevention of injury, even those whose claim was the implementation of more effective education strategies to the population, resulting in a diversity of subjectivities.

Yes (you can avoid). Cleaning the body and seek the doctor if there is any stain. (U3)

If the health centers were given more tips, manifest more on the subject. You have to show what it causes. (U24)

How could I avoid not knowing what it is? Even when don’t see? We avoid only when something comes up. (U25)

Any disease we can prevent, even the flu, because it is a disease that takes through the breath. (U38)

Seek medical help immediately, as soon as the symptoms come. (U21)

It perceives speeches with few specific approaches. Unhook the population of erroneous and empirical concepts is needed to make that discovery of new realities, so that it is possible to recognize health problems from a new perspective. 18

It is peculiar to creating conditions that integrate the individual to the social context of its coexistence, critically and participatory manner. Adherence to programs only occurs if the public sees part of the process of solving a problem. 18

The process of information and education should be implemented through teaching situations to provide restructuring of attitudes. Common sense says that health education is "to informing with as much content", but so professional only pass on what we seized over time, making guidelines manuals and technical guides are sovereign rules to follow little arousing the interest of the population to the situation. 1,15,18

There is no effective creation of environments in which there is a dialogic and participatory education. 18 The central challenge for educational activities in leprosy and primary health care lies not in enhancing the transmission of messages, either in communicative persuasion modeled strategies marketing, but in revising the assumption that the existence of elements of scientific information is sufficient to increase appropriate behavior for maintaining health.

With the presence of educational activities at community level, the enhancement of access to early diagnosis, the quantitative users on high for healing, the dissipation of stigmatization can occur, usually associated with populations less enlightened, and less favored. 1,13,16

- Association of leprosy to stigma

Regarding the social stigma it was asked if the participants knew someone with leprosy. Thus, 34,5% said yes, being the most referrals: neighbors (44,5%), family (22,4%) and friends (16,7%). Others were reported by 16,4% of participants.

Then be asked "are you afraid to get close to a person with leprosy"? It was found that 86,3% would not have fear. This is an interesting point to the predominance of justifications based on religious grounds, legitimizing the approach of patients under divine protection argument.

I'm not afraid of getting close, because I have faith in God. (U15)

I wouldn't say scared. I'm Catholic; I have faith in God, who is more than these diseases. (U20)

Because God is the one who frees us from all evil. (U40)

In antiquity, the lepers were seen as victims of an evil sent by God. This is a vision that can be shared even today. When we refer to the disease, there is an implicit consensus in the eyes of participants: patients. 10,12 Fear inspire fear by contagion, by association with its carriers, the meaning of leprosy.

Religious support is often sought in an attempt to overcome this situation, a fact that is associated with some degree of stigma. 11 Stigma is the impossibility of the fullness of life of the subject, which happens to be the target of various types of discrimination, contributing to their isolation in society. 11,12 It refers to a brand recognized for its "negative" aspect, for its lettering. 11,12

I'd come close but afraid of catching. (U12)

If the person is treating, no (I'm afraid to get close). You're crazy are you, for 'me' to catch! (U16)

Even living in modern times, with advanced ways of communication, and treatment available for leprosy, the company failed to eliminate the stigma that permeates the disease. A mark of disgrace physically present in the disfigurement of the leper is built to its darker side of society. 11

The practice of compulsory isolation used in every country in the world before the discovery of the cure was worse mode of punishment, disqualification, exile, rejection, deprivation and denial for a leper patient. 10

In Brazil, the extinction of the practice of compulsory isolation and replacing the term ‘leprosy’ compete to allay prejudice and fears linked to the disease. However, the movement and integration of leprosy in the social environment and its involvement in various activities as ways of blurring the disease, regarding humanization and socialization. 11
I have no bias; I don't think it is contagious enough to isolate the person. (U21)
No, I don't let that enter my mind. I don't have prejudice. (U19)
I've had (leprosy) and wouldn't be afraid no, (but) I can't tell who's never had. (U24)
I'm not afraid to come because we are all humans. (U13)

This last statement faithfully expresses leprosy in its broadest sense, running through the biological sphere, considering the man in its full entirety, including social, cultural and emotional aspects.

The deficit is not only the absence of educational actions, but also social interaction, which is so or more important for the leper than any functional and structural aspect.13 This relationship is fundamental to creating bonds of trust and confidence, contributing effectively to the healing process. Thus, the insertion of leprosy patients in the social environment deals directly in the dissipation of the negative stereotype, while contributing to the dissemination of guidelines regarding the grievance and to improving the quality of life.

**CONCLUSION**

Leprosy is related to the way in which the values and social practices are perceived and incorporated by the subjects, reflecting the context in which the subject is inserted and develops. It was found that knowledge about the disease features deficit as transmissibility, signs and symptoms and remains a disease association religiosity. Timely information favors the promotion of social change and acceptance, provided there is participation and engagement of the population, making the process of active and effective elimination, reverberating in early diagnosis, the appropriate treatment, the decrease of physical disability and social stigma.

Just saying that the disease has treatment and cure is not enough. There is the need for involvement of users, family and community in educational work and struggle to change the social conception.

It is extremely important that the health care team, a priori, be willing and able to providing assistance in primary health care, visualizing and acting on integrality of the patient and the community, envisioning not only biological, but also psychosocial aspects.

The social inclusion of people with leprosy is also a major factor and should rely on joint actions of the state, providing public policies that guarantee individuals social, economic and cultural conditions for their survival, and society, which should be linked to search and to the exercise of citizenship.

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Corresponding Address
Felipe Clementino Gomes  
Rua Antônio Félix, 1354  
Bairro São Sebastião  
CEP 58706-110 – Patos (PB), Brasil