ORIGINAL ARTICLE

SEXUALITY OF PEOPLE LIVING WITH LEPROSY: PERCEPTION AND REPERCUSSIONS

SEXUALIDADE DE PESSOAS QUEM VIVEM COM HANSENÍASE: PERCEPÇÃO E REPERCUSSÕES

Jaqueline Carvalho e Silva Sales1, Maura Pollyana Ribeiro de Araújo2, Mirele Cavalcante Coelho3, Vera Lúcia Evangelista de Sousa Luz4, Tereza Cristina Araújo da Silva5, Fernando José Guedes da Silva Júnior6

ABSTRACT
Objective: to analyze the perception of people with leprosy on their sexuality. Methodology: research in a qualitative nature, at a Reference Center for Leprosy, in the municipality of Teresina /PI/Brazil, with 11 patients. Data were collected by interviews with semi-structured forms, recorded and transcribed, with the use of Content Analysis. The study was approved by the Research Ethics Committee of Novafapi, 0302.0.043.000-10. Results: It was possible to define two categories: << Sexuality as a synonym for sex by looking at the leprosy patient >>, <<The repercussions of leprosy in the sexuality of people with the disease>>. Conclusion: leprosy because of clinical aspects and prejudice rooted changes the look of the bearer about sexuality; it is imperative that the nursing is able to provide integral assistance to a leprosy patient, envisioning from the biological aspects to the psychosocial factors, emphasizing their sexuality. Descriptors: Leprosy; Sexuality; Nursing.

RESUMO
Objetivo: analisar a percepção de pessoas com hanseníase sobre sua sexualidade. Metodologia: pesquisa de caráter qualitativo, num Centro de Referência em Hanseníase no município de Teresina /PI/Brasil, com 11 pacientes. Os dados foram coletados por entrevistas com roteiro semiestruturado, gravados e transcritos na íntegra, com uso da Análise de Conteúdo. O estudo foi aprovado pelo Comitê de Ética em Pesquisa da Novafapi, 0302.0.043.000-10. Resultados: foi possível a definição de duas categorias: << A sexualidade como sinônimo de sexo ao olhar do paciente portador de hanseníase >>, << As repercussões da hanseníase na sexualidade das pessoas com a doença >>. Conclusão: a hanseníase em virtude dos aspectos clínicos e do preconceito arraigado altera o olhar do portador acerca da sexualidade; é imperativo que o profissional de enfermagem esteja apto a prestar uma assistência que atue na integralidade do paciente portador de hanseníase, vislumbrando desde os aspectos biológicos até os psicossociais, destacando a sua sexualidade. Descritores: Hanseníase; Sexualidade; Enfermagem.

ARTICLE

1Nurse, Professor at the Faculty of Health, Human Sciences and Technology at Piauí/Novafapi. Piauí (PI), Brazil. Email: Jaqueline-carvalho@uol.com.br; 2Nurse at Faculty Ceut. Piauí (PI), Brazil. Email: mirelecc@hotmail.com; 3Nurse at Faculty Ceut. Piauí (PI), Brazil. Email: mirelecc@hotmail.com; 4Nurse at Faculty Ceut. Piauí (PI), Brazil. Email: vera.lucialuz@hotmail.com; 5Nurse at Faculty Ceut. Piauí (PI), Brazil. Email: titzerhi.cris@gmail.com; 6Nurse, Masters in Nursing from the Federal University of Piauí /PPGENF/UFPI. Piauí (PI), Brazil. Email: fernandoguedes123@hotmail.com

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INTRODUCTION

Leprosy is a disease of great relevance to public health due to its magnitude and its high level of incapacitating power. It is characterized by infectious and chronic disease which affects the economically active age range. Caused by Mycobacterium leprae, mandatory intracellular parasite, mainly affects the skin and peripheral nerves, but also manifests as systemic disease, and may affect joints, eyes, testicles, lymph nodes and other organs. Still associated with this clinical chart, is social discrimination, as well as economic losses that characterize the transcendence of this disease.1-2

Leprosy is a disease that when it is not diagnosed and treated early on, leads to the onset of disabilities and physical deformities that, in addition to limiting the productivity of the individual, is responsible for social marginalization, generating psychological repercussion. 3-4

In this sense, the transmission of leprosy is from person to person by intimate and prolonged contact with nasopharyngeal secretions of a patient without treatment. However, there are the patients with leprosy in its multibacillary form which constitute the major source of the disease’s transmission, due to reach shelter a large number of bacilli.5 The bacillus also presents a high infectivity and low pathogenicity, having a long incubation period, which varies from 2 to 7 years.1

Data from the World Health Organization (WHO) ranks Brazil among the seven countries in which there is a greater concentration of leprosy cases in the world, taking 2nd place, after India, in terms of new cases detected in early 2007 (43,436 cases, approximately 17.0 % of new cases in the world) and the 1st place in the Americas (with 93% of the cases of the American continent).6

It is observed that the leprosy is the disease of national importance that compromises men and women, causing serious economic and biopsychosocial cultural damage.7 The stigma and prejudice that still surround the disease, contribute in part to the social exclusion of its bearers.8

Adding to this the visible bodily changes (skin color, claw hands, among others) and the invisible (pain in the nerves, anesthetized areas); the result is a loss in part of the happiness, the quality of life and changes the perception of self-esteem of the person affected by leprosy.8 Losses and changes that may negatively influence them, among other aspects, the sexuality of patients.

The concept of sexuality discussed in this study, is not just in sex, contrary to what many people think. Sex is included in sexuality since it figures one of its important dimensions that lead to characterize it as an ability to connect to people, objects, ideas, ideals and life. It encompasses the whole body, the affective stimuli, availability, self-stimulation, imagination, opening to the encounters with other people, going beyond the union between man and woman or the pleasurable sensation through the genital organs.9-10

Guided by the assumptions listed above the interest to develop this research has been awakened. Therefore, the following question was raised: what is the perception of people with leprosy on their sexuality? Thus, the study aims to analyze the perception of people with leprosy on their sexuality.

METHOD

Descriptive and qualitative approach carried out in a State Reference Center in treatment of patients with leprosy, located in the northern area of the municipality of Teresina, PI - Brazil.

The research subjects were leprosy patients whose (spontaneous demand) consultations were held at the Center, for both sexes, 18 years of aged and accepted participation. There were 10 interviewees, four women and six men. Participation was voluntary, through reading and signing of the Consent Form (ICF), according to resolution no. 196/96 of the National Health Council, which deals with the ethical procedures for research involving human beings.

Data collection was started after authorization by the Center and the approval of the Research Ethics Committee of NOVAFAPI with CAA no. 0302.0.043 .000-10. The technique used for the interview was a semi-structured questionnaire. For the interview records an Mp3 was used as accepted by the subjects, with the purpose of reproducing it as accurately as possible for the answers given by leprosy patients during the interview for later transcription and data analysis.

Data collection was carried out during the months of November and December in 2010, at the Center’s auditorium through individual interviews with an average duration of 30 minutes each, during in the morning. To analyze the reports obtained, the content analysis was used.11
RESULTS AND DISCUSSION

The analysis of the data has allowed for the organization of them into two themes: Sexuality as a synonym for sex to the view the leprosy patient; and the repercussions of leprosy in the sexuality of people with the disease. After categorization of the data the interpretation of results began, articulating them with the theoretical framework, in addition to other concepts and ideas about sexuality and leprosy, following the proposed objectives.

- Sexuality as a synonym for sex in the view of the leprosy patient

The perception of sexuality has undergone numerous changes over the course of history, which eventually changed the way it is understood. Although there have been changes in the world and in contemporary man, this is still strongly associated only to something inherent with sexual behavior or activity. This fact is well illustrated in the testimonies below:

I don’t know what else to say because of this I have already stopped my life for some time now [...] my life today that I’m speaking about, you have no [...] I don’t even think [...] I don’t even stop to think about sex. (D1)

[...] It is very "brutal", only that I don’t do it without [...] I satisfy myself, I cum. In my sex life still, I am not "frustrated" because I’m not what I was before, but it not over yet. (D2)

[...] for men I think is very important, that if he does not practice he has no health; So I think that is a very important thing for the men’s life as for the woman’s life. (D3)

We can see that the differentiation between sexuality and gender has not yet been incorporated by many people, which is the product of family, religious or social values present throughout life. It is worth noting that for a long time, sexuality has remained under the perspective of a theme related only to the body, and the biological existence. It is considered as a biological instinct mainly directed towards reproduction. Up to half of the twentieth century it was understood and identified as genitality and heterosexuality, being conceived only as an observable effect in the sexual practice of individuals.

The conceptualization of sexuality as the mere physical act, which is seen as an instrumental character in favor of free expression of sexual desire human or for reproduction, transcended generations, since the first expressions of sexuality in this context dating back from the oldest people, that extolled the sacredness of the female body, male body, and, more specifically, the sexual encounter capable of generating life. This definition that still today is present in the conversation of many people when asked about their understanding on the topic. Another interesting point raised by the author is the fact that sexuality has become, for some, a basic area for the morality which seeks to determine concepts of legitimacy and illegitimacy for the practice, most of the times argued under religious precepts. In the testimony below, this is well illustrated, once the interviewees expressed to recognize as the only sexual practice socially accepted that adopted by the couple officially united in society, with the reproduction as the finality:

It’s normal because human life was to be this way, among couples. [...] because God left sexuality within marriage which is normal to build a family, but outside of marriage is not certain. (D4)

From the idea which has been discussed that sexuality configures the physical act of stress, provider bodily relief in pursuit of sexual pleasure, realizing that for some interviewees it refers to the scope of privacy and of intimate relations, as can be seen in the following report:

To me sexuality is something so particular, of each one, and so particular and just each one has a fingerprint [...] or you think in such a way, or act in a particular manner [...] (D5)

Until that moment we realized that the eyes of some leprosy patients of this research, as for their sexuality, expressed in the direction of sex, without taking into consideration its broader sense, which considers its symbolic context and can be defined by an aspect of human personality, expressed in various forms throughout the development of a person, beyond the sphere of genitality and manifesting itself in feelings and emotions.

However, it is important to note that there was a difference between the deponents who described sexuality in addition to the conception which has been described until now, as seen in the following statement:

Sexuality is to coexistence, it is the affective life between a man and woman, in a discreet, in a healthy way, in an amicable way and you have to have respect for the person with whom you are living [...] true love, is to have love for that person that you are giving yourself to, because sex is a thing very close, very intimate between you and the person in which you chose to take, it must be a safe thing [...] Sexuality I also think it is one thing that we all desire for...
the other, when you have, now sex by sex is not sexuality, and only momentary pleasure, instantaneously, now sexuality itself I think is something more profound, more respected, a thing more than consideration, love, love for the next one. (D6)

This testimony faithfully expresses sexuality in its broader sense, a part beyond the biological sphere, taking into account the man in its total completeness, including social, cultural and affective. In other words, sex is with the repository purpose of the survival of the species or for the range of sexual pleasure, is configured as one of the dimensions of sexuality, because it goes beyond this strict necessity, affecting all facets of human life, thus covering all of its existence.14

In this way, one can realize that the sexuality experience is related to the way in which the values and social practices are perceived and incorporated by the subjects, reflecting the sociocultural context in which the subject is inserted and develops.12 Soon after which the author adds, it is an integral part of the personality of the individual.

Therefore, it can be said that sexuality is a field that has different perceptions, which reflect the period, values, beliefs and culture in which the individual is inserted. While somewhat universal, since it is defined as something common to human life, beginning at conception and traversing its entire lifecycle, while it becomes something unique, unique to each individual, being experienced in many different ways.

Thus, based on what has been previously exposed and in testimonies, recognizes that the view on sexuality is still limited to its biological aspect. Sex, the fusion of bodies in order to procreate or meet the sexual desires of the individual, is still seen as synonymous with sexuality. People are just forgetting the real concept of sexuality, one that involves affective aspects and direct interventional efforts, such as determining factors of their sexuality. People are just forgetting the real concept of sexuality, one that involves affective aspects and direct interventional efforts, such as determining factors of their experiences.

- Repercussions of leprosy in the sexuality of people with the disease

This category defines the approach of sexuality for the leprosy patients under the influence of clinical signs and symptoms of the disease. Having the knowledge that leprosy is a clinical condition that could cause deformities and disabilities and may cause physical consequences that generate impact on social and emotional aspects; being that body image, the quotidian and the self-esteem for many of its bearers, end up being modified as seen by the following statement:

[...] My whole concern was regarding the issue, is the change in skin color, because it changes the color of the skin people ask, they question it, there I get very worried [...] has an effect on skin color, parches, you have to wear a protector (lotion). (D5)

The typical clinical signs and symptoms of the disease are manifested, especially in the peripheral nerves and skin (such as the face, arms, hands, legs and feet), generating sequel that are often more expressive than expected, leading the patient to the suffering. Leprosy has the ability to cause the loss of thermal sensitivity, tactile and painful, in addition to optic neuritis, motor changes and skin, ulcers, alopecia, blindness, among others.15

The skin lesions and in the peripheral nerves expressed in leprosy are results of the inflammatory process of the peripheral nerves, known as neuritis. Neuritis often becomes chronic and transforms into functional impairment of the nerve, also affecting the endocrine system, primarily related to testicular failure.16–17

Therefore, the bearer is faced with manifestations such as numbness, pain and thickening of the peripheral nerves, impotence and loss of muscle strength that eventually change their physical capabilities, and can even influence the experience of sexuality, because their desires, perceptions, body image, moral values, emotional and cultural are also adversely affected, as seen in the following statements:

[...] It gives me some cramps and I feel weakness in the nerves, I feel badly with this ordeal, and when the weather is hot I feel much more [...] I think that this ordeal of sexuality comes from the nerve and the disease is more in the nerve, and there also the person which is concerned with this disease throughout life [...] that is why I wanted to be good. (D7)

[...] A difficult time, because we has a problem with this, we always feel constant pain and that is not good. (D8)

The visible and non-visible bodily changes entail in impacts the daily life of the leprosy patient, resulting in a negative impact on self-image, the desire for concealment of the disease and the perception of the cure as the total elimination of the signs and sequel, returning to their life as it was before the disease.18

In this way, it is possible to observe how the clinical aspects of the disease affect the lives of a person, leaving them weakened in such a way that makes it impossible to carry out their daily activities, to the point that leprosy patients do not have physical and...
emotional conditions to continue living their lives as before, as observed in the following statements:

[...] I could not bear to work anymore, it was a lot of pain in my body, I felt tired, as it was I that I woke up in the morning and already I felt tired, without strength [...] I think leprosy even reacts in our psychological without us even knowing. (D9) [...] I am no longer the man that was before, I had a lot of strength, I worked, I still work, but it is not as it was once before and for me it has been difficult, because there are days that I am "stuck" in bed, there are days that I am well, there are days that I am not well. (D10)

In addition to compromising the physical performance, the clinical manifestations affect also the body image, it is understood by the image one has of their own body, developed from a social and cultural referential that is more associated with the imagery of that with reality, having a greater concern in to fit in what is socially desirable. Soon, the one who flies or does not fit within the beauty standards determined by society to which they are inserted, has their self-esteem negatively affected, generating dissatisfaction with their body and image.  

Therefore, upon the foregoing and that was knowing that leprosy among the various clinical signs and symptoms it causes, provokes skin changes ranging from whitish, reddish or brownish nodules, dry skin, platelets to infiltration, it is important to note that these changes end up interfering with the aesthetics, the image of the individual, generating feelings of embarrassment and shame, as noted in the following testimony:

[...] Due to a very innocent little spot, and as I see much my body and it does not disappear, I felt that it was also velvety, was different from other wounds, spots, marks that there are on our bodies and also by the pains in my body, I felt numbness in my hands, numbness in my feet. My toenails looked bark from the jabuti tree, they were rough and yellow, they were not normal nails [...] I think it does all this with us, transforms the body of people, so that we are left with shame, our bodies change. (D9)

Soon afterwards, on the basis of the testimony above, the visible body changes entailed by leprosy affect the self-image of the patient, which in association with physical impairment; can cause a series of difficulties and changes in the psychological and emotional aspects of the individual, with negative repercussions in their sexuality. This is because any change that will alter the body image, making it different from the body of another, brings several repercussions to the individual, between them, in their sexuality.20

Living with the disease entails difficulties and changes for the patient’s life, once the basic aspects such as locomotion, coexistence and interpersonal relations will represent a problem that not only is perceptible to them, but also to the people that surround them.

CONCLUSION

Leprosy, despite the existence of its cure and being non-transmissible right after the start of treatment, is still associated with the image of a degenerative and incurable disease that can be passed by a simple skin contact. Since sexuality is still strongly linked to moral issues and influenced by myths, taboos and prejudices, in the case of a subject to be approached with caution.

It was also observed that the repercussions in the body due to the clinical manifestations of the disease and the fear of rejection on the part of relatives, friends and other people that surround them, negatively affected the self-esteem of patients with leprosy, making it difficult for him sharing feelings and relate, taking it in the majority of the times the deprive yourself to live satisfactorily for their sexuality during this moment of their life. This is a disturbing fact, since this can lead to inadequate adherence to treatment, and generate psychological repercussions that will make the recovery process difficult.

Thus, it is of paramount importance that the nurse is willing and able to provide assistance to and act in full view of the patient with leprosy, envisioning from the biological to the psychosocial aspects, including regard to their sexuality. Soon afterwards, it is necessary that the nurse, during the nursing consultation, should not only be limited to examine them and the giving of medication, but also be ready to explain and guide them as to the maintenance of their sexuality, taking into consideration that each has a conception formed on this subject, which is a reflection of family values, social and cultural acquired throughout their life.

Therefore, it is worth emphasizing that the nursing professional to fully assist the leprosy patient, both in the individual and collective sense, will be helping them cope with the disease and the maintenance of social life, without the risk of sequels in body and soul.
REFERENCES


