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Perceived sexual dysfunction and factors attributed by women with leprosy

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Abstract

Leprosy is an infectious disease of slow evolution, high infectivity and low pathogenicity, which presents dermato-neurological signs and symptoms. The change in the sexual pattern caused by female sexual dysfunction is a complication that can be experienced by women with leprosy, causing a negative impact on quality of life. The objective of this study was to identify the perceived sexual function and factors attributed by women with leprosy. This descriptive, cross-sectional study was carried out in two dermatology outpatient clinics in the city of Fortaleza, Ceará, with 76 women with leprosy. An interview form was used with socioeconomic and clinical variables, and application of the Female Sexual Function Index. Young adulthood prevailed, with unfavorable socioeconomic conditions, and multibacillary forms. The perception of sexual dysfunction was predominant among the interviewees (60.5%), who cited as factors related to self-image (26.0%) and changes in sexual desire (26.0%). The domains with the greatest change were: satisfaction (R=3.06), arousal (R=3.78), desire (R=3.79), and orgasm (R=3.79). The approach to the sexual function of women with leprosy should be carried out by health professionals, in order to promote greater sexual and personal satisfaction for the patient.

Keywords: Women's Health. Leprosy. Sexual Behavior.

INTRODUCTION

Leprosy is an infectious disease which evolves slowly, is highly infective, and has a low pathogenicity, caused by Mycobacterium leprae that presents dermato-neurological signs and symptoms. Throughout history, this has been described as a stigmatizing disease due to physical deformities related to untreated patients and the lack of knowledge about aspects related to the disease, such as the transmission route[1].

The World Health Organization (WHO) launched the Global Leprosy Strategy 2021–2030, which aims to implement plans, goals, and strategies for the interruption of transmission and elimination of the disease, with an emphasis on combating stigma and guaranteeing human rights[2].

In 2020, there were 127,396 new cases of leprosy in the world. Among the 23 priority countries for the control of the disease, Brazil ranked second in the number of new cases of leprosy, totaling 17,979 reports[3].

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Although the disease affects proportionately more in men, in recent years there has been a reduction in the difference between the sexes, affecting women of full reproductive age, which can lead to biopsychosocial and economic losses[2]. According to the WHO, in 2020, 38.6% of new cases were women, and in five countries the prevalence of females was over 60%[2].

Sexuality is a complex phenomenon with multiple sides, which incorporates biological, historical, and cultural aspects of a human being, constituting an inseparable dimension. The exercise of sexuality is closely linked to the production of pleasure and its many quantitative and qualitative variations, linked to affectivity, personal relationships, as well as eroticism, and sexual intercourse[4].

The female sexual response cycle is negatively influenced by psychological factors, including anxiety, low self-esteem, body image perception disorders, and fear of rejection, aspects that permeate the reality of women with leprosy[4].

The change in the sexual pattern caused by female sexual dysfunction is a complication often faced by women with leprosy, producing a negative impact on quality of life. Such dysfunction can be classified into three categories: dysfunction in sexual desire/arousal, orgasm dysfunction, and genito-pelvic pain[5].

For moral, social, and cultural reasons, the sexual function of people affected by leprosy is little explored by the health team. This reality can also be due to lack of knowledge or difficulty in talking about this subject by health professionals, since there is a need to know the limitations and problems of the patient.

Therefore, the present study aims to identify the perceived sexual function and factors attributed by women with leprosy.

METHODOLOGY

This is a descriptive, exploratory and cross-sectional, quantitative study, developed in Fortaleza, from January to May 2018, in two special healthcare centers for leprosy in the State of Ceará.

Seventy-six women with leprosy who met the following inclusion criteria were interviewed: age 18 years or older and self-declaring sexually active. Regarding the exclusion criteria, the participant could not be in the first month of treatment for the disease, since the scale used to assess sexual function investigates the sexual aspects of the previous four weeks.

During the interview, a semi-structured form was used, which contained questions related to sociodemographic, economic, and clinical variables, such as: age, marriage status, education, clinical form of leprosy, treatment regimen in use, and degree of physical disability at diagnosis. Topics related to the participant's sexual function were also included, such as: frequency of sexual intercourse, perceived change in her or her partner's sexual performance, and factors attributed by the participant to a possible perceived sexual dysfunction.

For the evaluation of sexual function, the Female Sexual Function Index (FSFI) was applied, translated and validated for the Brazilian reality. The FSFI is a questionnaire created to assess the female sexual response. It consists of nineteen questions that assess sexual function in the previous four weeks, including topics such as: frequency of sexual desire and

arousal, vaginal lubrication, orgasm, sexual satisfaction, and pain[6].

The FSFI analysis was performed by pooling responses in six different domains: desire, arousal, lubrication, orgasm, satisfaction, and discomfort/pain. The scores for each domain were multiplied by the correction factor and added. The final score ranges from two to 36 points. The cut-off point adopted as a determinant for a higher risk of sexual dysfunction was a score lower than 26[6].

The data were organized in the Microsoft Excel 2013 program, later transported to the STATA version 13 program, the software used for data processing. Initially, a descriptive analysis was performed through the distribution of frequencies, means, and Standard Deviation (SD) to characterize the sample.

The study complied with the legal ethical principles contained in Resolution No. 466/2012 of the National Health Council and was approved by the Ethics Committee of the Federal University of Ceará (Consubstantiated opinion No. 1.817.368, in 2016, CAAE: 61722716.0.0000.5054). All study participants signed the Informed Consent Form.

RESULTS

The mean age of the participants was 45.9 years (SD=16.6), ranging from 18 to 81 years. The profile revealed a predominance of women residing outside the city where the disease was monitored (56.6%), lesser education with an average of 6.4 years of study, a family income between 1 and 2 minimum wages (73.6%), and in a fixed partnership (50%) (Table 1).

As for clinical characteristics, the most prominent clinical form was borderline (48.6%), in which the predominant treatment regimen was multibacillary (60.4%). Most of the interviewees (67.2%) did not have physical disabilities caused by leprosy.

In the analysis of the sexual life of the participants, 48 (63.1%) women reported having sexual intercourse one or more times per week, and 46 (60.5%) reported having noticed a change in their sexual behavior after the diagnosis of leprosy (Table 2).

The predominant factors attributed to this change were the shame of changes in the skin (26.0%), the decrease/absence of sexual desire (26.0%), the fear of transmitting the disease to their partner (17.3%), and symptoms related to drug treatment (15.2%).

The total FSFI score of the participants ranged from 17.0 to 34.4, with a mean of 24.1, where 60 (78.9%) women had a total score lower than 26, a result that points to an increased risk of sexual dysfunction in the studied group, including a higher number than women who reported perceived sexual change (60.5%). Regarding the domains, it is noteworthy that the domain with the worst average performance was sexual satisfaction, and the domain with the best evaluation was the domain of pain or discomfort (Table 3).

In the *desire* domain, the frequency and degree of sexual *desire* or interest was addressed. As for frequency, most women (36.9%) reported that, in the last 4 weeks, they rarely felt desire or interest, and that the degree of desire was moderate (47.4%).

In the *arousal* domain, the majority (30.2%) of the participants reported that they rarely (less than half the time in 4 weeks) felt sexually aroused during sexual activity or intercourse. As for the degree and security to get excited, the most prominent result was moderate for both (40.8% and 59.2%, res-

pectively). With regards to the frequency of satisfaction with their sexual arousal, 25 (32.9%) women reported that they were rarely satisfied with their sexual arousal during sexual activity or intercourse.

In the *lubrication* domain, 33 (43.4%) women claimed to maintain vaginal lubrication during sexual intercourse, but 22 (28.9%) reported that it was slightly difficult to maintain lubrication until the end of sexual activity.

In the *orgasm* domain, the most prominent responses regarding the frequency of reaching climax were some and a few times (23.7%, for both) in the last 4 weeks, with 39.5% of women stating that it was slightly difficult to reach orgasm, and 36.9% moderately satisfied with their ability to reach orgasm.

In the *satisfaction* domain, 26 (34.2%) participants were dissatisfied with their emotional closeness to their partner during sexual activity. Overall, 28 (36.9%) participants reported being moderately satisfied with their sexual relationship with their partner and with their sex life.

In the *pain* domain, most participants (53.9%) stated that, in the last four weeks, they almost never or never felt discomfort or pain during vaginal penetration, and 55 (72.4%) also did not feel discomfort or pain after vaginal penetration.

Table 1 - Sociodemographic and clinical characteristics of women with leprosy, Fortaleza, Ceará, Brazil, 2018.

Variables	n (%)
Age	
18 – 39	24 (31.7)
40 – 59	30 (39.4)
≥ 60	22 (28.9)
City of residence	
Fortaleza	33 (43.4)
Other municipalities	43 (56.6)
Relationship status	
Fixed partner	38 (50.0)
Single	31 (40.8)
Eventual partner	07 (9.2)
Education	
0 to 3 years	21 (28.0)
4 to 5 years	21 (28.0)
6 to 9 years	19 (25.3)
10 years or more	14 (18.7)
Family Income in Minimum Wage (MW)	
< 1 MW	09 (11.8)
1 - |2 MW	56 (73.6)
>2 - |3 MW	07 (9.2)
> 3 MW	04 (5.4)
Clinical form	
Undetermined	04 (5.4)
Tuberculoid	23 (30.2)
Borderline	37 (48.6)
Virchowiana	12 (15.8)
Treatment schedule	
Paucibacillary	26 (34.2)
Multibacillary	46 (60.4)
Alternative	04 (5.4)
GD	
0	51 (67.2)
1	22 (28.9)
2	02 (2.6)
Not reported	01 (1.3)

Table 2 – Characteristics of the sexual function of women with leprosy. Fortaleza, Ceará, Brazil 2018.

Variables	n (%)
Frequency of sexual intercourse weekly	
One or more times	48 (63.1)
Eventual relationship, without defined frequency	28 (36.9)
Perceived sexual change after diagnosis	
Yes	46 (60.5)
No	30 (39.5)
Factors attributed to sexual change after diagnosis (n=46)	
Ashamed of skin changes	12 (26.0)
Decreased/absence of sexual desire	12 (26.0)
Fear of transmission of the disease to the partner	08 (17.3)
Symptoms related to drug treatment	07 (15.2)
Distancing from partner	05 (10.8)
Pain	02 (4.7)

Table 3- Distribution of the mean of the FSFI domains in women with leprosy. Fortaleza, Ceará, Brazil, 2018.

Domains	Risk of sexual dysfunction	
	Yes (60 – 78.9%)	No (16 – 21.1%)
Desire (R*= 3.79)	3.85	5.45
Arousal (R= 3.78)	3.40	4.99
Lubrication (R= 3.96)	3.87	4.25
Orgasm (R= 3.79)	3.53	4.61
Satisfaction (R= 3.06)	2.67	4.32
Pain/Discomfort (R= 5.34)	5.28	5.56

*R: Average of all women.

DISCUSSION

The sociodemographic and clinical profile of the interviewees was similar to other studies in the same population, in which young adulthood, unfavorable socioeconomic conditions, presence of multibacillary forms, and absence of physical disabilities at the time of diagnosis predominated[7-8].

The sexual dysfunction perceived in women with leprosy was predominant, and presented as factors attributed to altered body image, decreased libido, and fear of transmission to the partner.

Physical appearance is something important for the female gender, mainly because women are, in most cases, identified in terms of their image. The manifestations of leprosy can alter the female appearance, leaving them unsuitable for socially established aesthetic standards. This point directly interferes with their sexual activity, which can lead to a decrease in libido and sexual availability, factors identified in the women in this study. Furthermore, the feeling of rejection, the decrease in

self-esteem and fear of abandonment by their partner are also highlighted[9].

The aesthetic and functional dimension of the individual, especially with regards to the female gender, are profoundly affected even after leprosy is cured. The woman's perception of her body is based on bodily changes and their repercussions, mainly due to the presence of injuries and physical disabilities. For women, the image of a beautiful and perfect body is associated with the absence of changes to the skin[10].

In the affective, social, and sexual sphere, we can see that the reality of women with leprosy is different from the male reality. While for men, the biggest obstacle to a full relationship with their partner would be the difficulty of erection and sexual impotence, explained by the occasional testicular invasion by the lepromatous bacillus, triggering a decrease in basal concentrations of testosterone and testicular lesions; for women, the psychological component has a lot of weight, as their self-perception and self-esteem are greatly affected[1,11].

In this study, it was noticed that most women with leprosy felt insecure with their body image due to dermatological changes, and that they decreased sexual activity and touching for fear of transmitting the disease through sexual intercourse or saliva, while others feared being abandoned by their partner.

Women with leprosy have a negative self-perception of appearance. In affective relationships there are reports of sexual unavailability, disinterest, and divorce. Moreover, they reported a negative influence of the effects of multidrug therapy and physical symptoms on the performance of sexual activity[11-12].

A survey carried out in Nepal, with 30 women with leprosy and other physical disabilities, which aimed to investigate and compare factors related to the perception of life and sexuality of these women, revealed that women with leprosy seemed to face more problems in their marital and sexual relationships than those with only a physical disability. Furthermore, most of the interviewees said they had problems related to sexual relationships, where partners abstained from relationships and slept in separate beds, while the women were undergoing treatment, experiencing the stigma regarding the transmission of the disease[13].

The stigma related to the disease can also be experienced by other family members of the person affected by leprosy, including in their personal relationships. In a qualitative study carried out in Ethiopia, it was demonstrated that people affected by leprosy and their relatives had difficulties in finding a partner or maintaining their marriage, as they were considered a threat to the well-being of the community[14].

As the signs of leprosy and its treatment become visible, women more often avoid social contact, including hiding the disease from family members and partners, as demonstrated by most of the women (58%) interviewed in a survey in Indonesian district[15].

For women with pathologies or alterations in their aesthetic dimension, sexuality is still a taboo. Many women are still afraid to talk about their sexuality due to the normative culture we still have in our society. The support and help of their partner is important for women with leprosy, as it positively affects the coping with the disease in society, as well as the empowerment of their body, valuing their self-image.

Sexuality is considered an intimate and relational dimension that makes up people's subjectivity and their relationships with their peers and the world. It also refers to the emotion that sex can produce, transcending physical definitions. It has complex, multifaceted meanings that concentrate a great deal of subjectivity. But it also involves physical issues

such as loss of libido, erectile dysfunction, pain, among others, making sexuality and the sexual act secondary in their lives[11].

Thus, sexuality is not an isolated axis in the life of the individual, but a dimension interconnected with other areas of life, such as health, living in society, self-perception and self-image, education, among others, which can positively or negatively interfere in this vast field.

In view of the above, health professionals are advised to pay more attention during follow-up consultations for these women, where the professional must clarify the patient's and her partner's concerns, especially those that can harm self-image, such as changes in skin color caused by clofazimine, leprosy reactions, and disabilities[1]. As well as adopting a welcoming attitude towards the patient's reports and fears. If necessary, they should request the presence of the partner, to demystify some beliefs about the disease, and allow the family to support and be part of the treatment and recovery process.

CONCLUSION

The sexual function of women with leprosy is a topic that deserves to be highlighted, given its impact on quality of life, especially in social and affective relationships, and due to the lack of discussion of this topic in the scientific society.

In this study, women with leprosy showed a profile compatible with other studies in which young adulthood, the presence of unfavorable socioeconomic conditions, and the disease by the multibacillary forms prevailed. Perceived sexual dysfunction was predominant among the interviewees, with factors associated with self-image and decreased sexual desire. It is noteworthy that the percentage of women at risk for sexual dysfunction detected by the application of the FSFI was higher than that spontaneously reported by the participants. Regarding the domains evaluated through the FSFI, changes were noticed in most domains, with an emphasis on the domains of satisfaction, arousal, desire, and orgasm.

The findings reveal that women affected by leprosy face difficulties in maintaining sexual function, mainly due to intrinsic factors. Thus, it is imperative that there is an available and welcoming environment for the promotion of sexual health, so that these factors are exposed and discussed, as they are often related to fear of disease transmission, drug treatment, self-perception, and stigma.

As a limitation of this study, we highlight the cross-sectional design and the reduced sample size, as there were refusals to participate due to the sexual content addressed in the questionnaire and scale.

Author statement CRediT

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