

ORIGINAL ARTICLE

QUALITY OF LIFE OF PATIENTS WITH LEPROSY REACTIONS

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ABSTRACT

Purpose: To evaluate the impact of leprosy on the quality of life of patients with leprosy reactions. **Method:** A cross-sectional and quantitative study of 40 patients in January 2017 at a referral outpatient clinic in Paraíba using a questionnaire containing sociodemographic and clinical-epidemiological data and an instrument for quality of life assessment, The World Health Organization Quality of Life. **Results:** It was observed that the dimension of social relations stood out (64.38) with a better score for quality of life, highlighting the high satisfaction (85%) of the individuals. The physical domain presented the lowest score (51.07), with 50% of reports of limitation to perform activities due to pain, but all dimensions scored above 50 points, leading to a good quality of life. **Conclusion:** The pathophysiology of reactions, living conditions and health policies can influence the quality of life of patients, reflecting on the need to foster public policies for this population.


DESCRIPTORS: Leprosy; Neglected diseases; Inflammation; Quality of life; Secondary Health Care.


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QUALIDADE DE VIDA DE PACIENTES COM REAÇÕES HANSÊNICAS**RESUMO**

Objetivo: avaliar o impacto da hanseníase na qualidade de vida de pacientes com reações hansênicas.

Método: estudo transversal e quantitativo realizado com 40 pacientes em janeiro de 2017 em ambulatório de hospital paraibano de referência utilizando questionário contendo dados sociodemográficos e clínico-epidemiológicos e instrumento para avaliação da qualidade de vida, The World Health Organization Quality of Life.

Resultados: observou-se que a dimensão relações sociais sobressaiu-se (64,38) com melhor escore para qualidade de vida, destacando-se elevada satisfação (85%) dos indivíduos. O domínio físico apresentou menor escore (51,07), com 50% de relatos de limitação para realização de atividades devido à dor, todavia todas as dimensões pontuaram acima de 50 pontos, direcionando para boa qualidade de vida.

Conclusão: a fisiopatologia das reações, as condições de vida e as políticas de saúde são capazes de influenciar a qualidade de vida dos pacientes, refletindo-se sobre a necessidade de fomento às políticas públicas para essa população.

DESCRITORES: Hanseníase; Doenças Negligenciadas; Inflamação; Qualidade de Vida; Atenção Secundária à Saúde.

CALIDAD DE VIDA EN PACIENTES CON REACCIONES HANSÊNICAS**RESUMEN:**

Objetivo: evaluar el impacto de la lepra en la calidad de vida de pacientes con reacciones hansênicas.

Método: estudio transversal y cualitativo realizado con 40 pacientes en enero de 2017 en el área de atención ambulatoria del hospital de Paraíba de referencia, por medio de un cuestionario que contenía datos sociodemográficos y clínico-epidemiológicos y de un instrumento para evaluar la calidad de vida: The World Health Organization Quality of Life.

Resultados: se observó que las dimensiones sociales se destacaron (64,38) con una mejor puntuación para la calidad de vida, especialmente el elevado nivel de satisfacción (85%) de los individuos. El dominio físico presentó una puntuación más baja (51,07), con el 50% de reportes de cierta limitación para realizar actividades debido al dolor; pese a ello, en todas las dimensiones se obtuvieron puntuaciones superiores a los 50 puntos, lo que apunta a una buena calidad de vida.

Conclusión: a fisiopatología de las reacciones, las condiciones de vida y las políticas de salud pueden influenciar la calidad de vida de los pacientes, lo que se refleja sobre la necesidad de fomentar las políticas públicas destinadas a esa población.

DESCRIPTORES: Lepra; Enfermedades desatendidas; Inflamación; Calidad de vida; Atención secundaria de la salud.

INTRODUCTION

Leprosy is a disease with considerable epidemiological numbers in underdeveloped countries such as Brazil and, in the state of Paraíba,^(1,2) it is also infectious, polymorphic and disabling, despite its low pathogenic power caused by *Mycobacterium leprae*. The preference of the bacillus for skin cells and peripheral nerves causes alterations in the sensory, motor and tegumentary levels, which can lead to physical disabilities and deformities.⁽³⁾

Leprosy reactions are one of the main problems in the management of patients.⁽⁴⁾ These are characterized by acute inflammatory complications arising from immune instability against the bacillus and may arise before, during or after drug treatment, with duration and frequency varying according to the clinical form of the disease.⁽⁵⁾

Reactions may be classified as type I (reverse) or type II (*erythema nodosum leprosum*) depending on the type of immunity involved and on the characteristics of the lesions. In type I reactions, there is involvement of cellular immunity with the appearance of spots or plaques, presence of infiltrations, edema, pain and nerve thickening. In type II, there is a greater participation of humoral immunity with the presence of painful erythematous subcutaneous nodules, fever, joint pain and malaise.⁽⁶⁾

Given the significant proportion of patients who develop reaction states and that these are largely responsible for the disabling potential of the disease, their ability is recognized to limit activities, restrict social participation and interfere with the quality of life (QoL) of the patients.⁽⁷⁾

The current concepts of quality of life are composed of a multitude of dimensions that depend on the area of interest and are often adopted as a synonym for health, happiness, personal satisfaction, conditions and lifestyle.⁽⁸⁾ The concept explained by the World Health Organization (WHO); however, defines QoL as a reflection of the individuals' perception of their needs or, even, denial of opportunities to achieve happiness and personal fulfillment, with independence of their physical or social and economic health conditions.⁽⁹⁾

Considering that the patients may experience the onset of physical pain, medication dependence, difficulty in performing activities of daily living and acceptance of physical appearance, development of negative thoughts, lack of social support, among other situations, the importance of the impact that the disease can have about their QoL is understood, as well as their potential for aggravation due to leprosy reactions.

In this perspective, it is relevant to evaluate the relationship between QoL and the presence of leprosy reaction among patients, allowing subsidy for the promotion of effective care strategies. Therefore, the objective is to evaluate the impact of leprosy on the QoL of patients with leprosy reactions.

METHOD

This is a cross-sectional, descriptive and quantitative study conducted with patients undergoing treatment for leprosy and for leprosy reactions at a specialized referral center in the state of Paraíba.

From 127 patients who were undergoing treatment during January 2017, a convenience sample was chosen, and 40 subjects were selected. The inclusion criteria established were individuals over 18 years of age, undergoing multi-drug therapy from the second dose, and undergoing treatment for leprosy reactions type I or II. Individuals with impaired, self-reported or perceived cognition were excluded, in view of the impossibility to answer the questions proposed by the data collection instrument.

Data collection was performed with two structured instruments. The first contained sociodemographic and clinical-epidemiological data. The second was The World Health Organization Quality of Life (WHOQOL-BREF), an instrument used to subjectively measure QoL and that has good acceptability, application brevity and validation in several cultures, having been validated in Brazil.⁽¹⁰⁾

The final version of WHOQOL-BREF consists of 26 questions, two concerning general aspects, and 24 divided into four dimensions: physical (7), encompassing issues related to pain and discomfort, energy and fatigue, sleep and rest, mobility, activities of daily life, medication dependence and work capacity; psychological (6), asking the individual about the presence of positive/negative feelings, thinking, learning, memory and concentration; self-esteem, body image and appearance; social (3), which concerns personal relationships, social support and sexual activity; and environmental (8) related to physical safety and protection, home environment, financial resources, health care, new information and skills, recreation and leisure, physical environment and transportation.⁽¹⁰⁾

The score for each question has a Likert answer ranging from 1 to 5 points, a high score being indicative of good QoL, except for three questions (3 - pain and discomfort, 4 - need for medical treatment and 26 - negative feelings), which have negative content and, therefore, should have their score inverted.⁽¹¹⁾

Data was tabulated in Microsoft Office Excel 2016 and analyzed, and a cluster of questions per dimension was performed to calculate their mean values.⁽¹²⁾ The cutoff points defined for QoL assessment considered the midpoint of the response scale, thus, as the scores range from 0 to 100, ≤ 50 points were considered unsatisfactory for QoL and scores > 50 were considered satisfactory.

It is noteworthy that this study is part of the project "Self-care behavior in leprosy patients", approved by the Ethics and Research Committee of the Health Sciences Center of the Federal University of Paraíba, Opinion No. 1,824,693.

RESULTS

The sample consisted of 40 patients with a mean age of 45 years old, male predominance: 23 (57.5%), with elementary school education: 20 (58%), and income less than or equal to a minimum wage: 29 (72.5%).

Clinically, the classification of multibacillary type 40 (100%) prevailed; dimorphic clinical form 22 (55%); positive smear microscopy 27 (67.5%) and leprosy reaction type I 28 (70%).

In the analysis of the answers from WHOQOL-BREF, it is observed that the dimension of social relations stands out with the best QoL score, while the physical dimension presented the lowest score. However, it is noteworthy that all dimensions were above 50 points, i.e., directed to a satisfactory QoL, as shown in Figure 1.

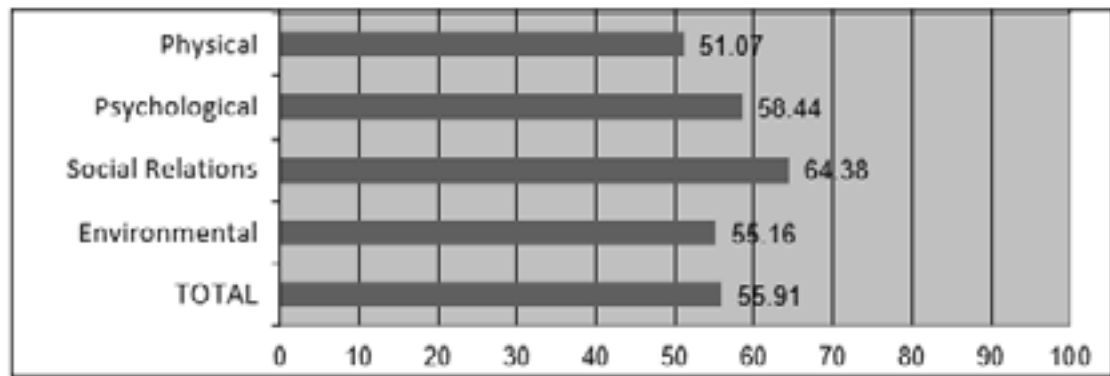


Figure 1 – Distribution of QoL mean values, according to the distribution by dimensions of the WHOQOL-BREF questionnaire. João Pessoa, PB, Brazil, 2018

Source: Own search.

Fragmenting the dimensions of the questionnaire among the items that compose it, in Tables 1, 2, 3, 4 and 5 the percentages are observed according to the instrument's response scale, emphasizing the subjectivity of the QoL assessment among individuals in some items, for example in the overall assessment, where responses were 40% for neither bad nor good and 45% for good. Worthy of mention are items Q12, which refers to financial conditions, and Q14, related to leisure, belonging to the social relations domain, as the only ones in which the highest percentages were present in the "nothing or very little" response scale.

Table 1 – Analysis of the general aspects of the WHOQOL-BREF questionnaire, according to questionnaire items and scale. João Pessoa, PB, Brazil, 2018

General Aspects	n	%	n	%	n	%	n	%	n	%
	Very poor		Poor		Not bad Not good		Good		Very good	
Q-1: How would you rate your quality of life?	1	2.5	4	10	16	40	18	45	1	2.5
Q2: How satisfied are you with your health?	n	%	n	%	n	%	n	%	n	%
	Not at all		Very little		More or less		Quite		Extremely	
	5	12.5	7	17.5	7	17.5	21	52.5	0	0

Source: Own search

Table 2 – Analysis of the physical domain of the WHOQOL-BREF questionnaire, according to questionnaire items and scale of answers. João Pessoa, PB, Brazil, 2018 (continues)

Physical Domain	n	%	n	%	n	%	n	%	n	%
	Not at all		Very little		More or less		Quite		Extremely	
Q-3: To what extent do you think your (physical) pain prevents you from doing what you need?	6	15	8	20	5	12.5	1	2.5	20	50

Q-17: How much do you need any medical treatment to lead your daily life?	1	2.5	8	20	17	42.5	3	7.5	11	27.5
	Not at all		Very little		Average		Very much		Completely	
Q-10: Do you have enough energy for your daily life?	3	7.5	6	15	15	37.5	14	35	2	5
	Very bad		Poor		Not Bad/Not Good		Good		Very good	
Q-15: How well are you able to get around?	3	7.5	7	17.5	9	22.5	8	20	13	32.5
	Very dissatisfied		Dissatisfied		Not Satisfied/Not Dissatisfied		Satisfied		Very satisfied	
Q-16: How satisfied are you with your sleep?	5	12.5	2	5	11	27.5	19	47.5	3	7.5
Q-17: How satisfied are you with your ability to perform your day-to-day activities?	5	12.5	4	10	9	22.5	21	52.5	1	2.5
Q-18: How satisfied are you with your ability to work?	9	22.5	5	12.5	5	12.5	20	50	1	2.5

Table 3 – Analysis of the psychological domain of the WHOQOL-BREF questionnaire, according to questionnaire items and response scale. João Pessoa, PB, Brazil, 2018

Psychological Domain	n	%	n	%	n	%	n	%	n	%
	Not at all		Very little		More or less		Quite		Extremely	
Q-5: How much do you enjoy life?	6	15	7	17.5	12	30	14	35	1	2.5
Q-6: To what extent do you think your life has meaning?	1	2.5	1	2.5	7	17.5	27	67.5	4	10
Q-7: How much can you concentrate?	1	2.5	3	7.5	5	12.5	27	67.5	4	10
	Not at all		Very little		Average		Very much		Completely	
Q-11: Can you accept your physical appearance?	2	5	5	12.5	6	15	18	45	9	22.5
	Very dissatisfied		Dissatisfied		Not Satisfied/Not Dissatisfied		Satisfied		Very satisfied	
Q-19: How satisfied are you with yourself?	2	5	5	12.5	5	12.5	26	65	2	5
	Never		Sometimes		Frequently		Very frequently		Always	
Q-26: How often do you have negative feelings such as moodiness, despair, anxiety, depression?	5	12.5	3	7.5	4	10	17	42.5	11	27.5

Source: Own search

Table 4 – Analysis of the social relations domain of the WHOQOL-BREF questionnaire, according to questionnaire items and response scale. João Pessoa, PB, Brazil, 2018

Social Relations Domain	n	%	n	%	n	%	n	%	n	%
	Very dissatisfied		Dissatisfied		Not Sat./Not dissat.		Satisfied		Very satisfied	
Q-20: How satisfied are you with your personal relationships (friends, relatives, acquaintances, colleagues)?	1	2.5	3	7.5	6	15	28	70	2	5
Q-21: How satisfied are you with your sex life?	2	5	8	20	3	7.5	25	62.5	2	5
Q-22: How satisfied are you with the support you get from your friends?	1	2.5	5	12.5	6	15.0	24	60	4	10

Source: Own search

Table 5 – Analysis of the environmental domain of the WHOQOL-BREF questionnaire, according to questionnaire items and response scale. João Pessoa, PB, Brazil, 2018

Environmental Domain	n	%	n	%	n	%	n	%	n	%
	Not at all		Very little		More or less		Quite		Extremely	
Q-8: How safe do you feel in your daily life?	1	2.5	7	17.5	9	22.5	22	55	1	2.5
Q-9: How healthy is your physical environment (weather, noise, pollution, attractions)?	2	5	10	25	25	62.5	3	7.5	0	0
	Not at all		Very little		Average		Very much		Completely	
Q-12: Do you have enough money to meet your needs?	10	25	13	32	12	30	5	12.5	0	0
Q-13: How available to you is the information you need in your daily life?	1	2.5	7	17.5	14	35.5	15	37.5	3	7.5
Q-14: To what extent do you have opportunities for leisure activity?	16	40	14	35	6	15	2	5	2	5
	Very dissatisfied		Dissatisfied		Not Satisfied/Not Dissatisfied		Satisfied		Very satisfied	
Q-23: How satisfied are you with the conditions of your place of residence?	1	2.5	4	10	5	12.5	24	60	6	15
Q-24: How satisfied are you with your access to health services?	2	5	4	10	3	7.5	28	70	3	7.5
Q-25: How satisfied are you with your means of transport?	4	10	2	5	3	7.5	30	75	1	2.5

Source: Own search

In Figure 2 it is possible to visualize the influence of the items in the construction of the dimensions scores. Corroborating with previous data, it was found that seven items (pain and discomfort; dependence on medical treatment; working capacity; positive feelings; negative feelings; financial resources; recreation and leisure) were below the score of 50 points, negatively influencing QoL within its dimensions and in the overall analysis of the instrument.

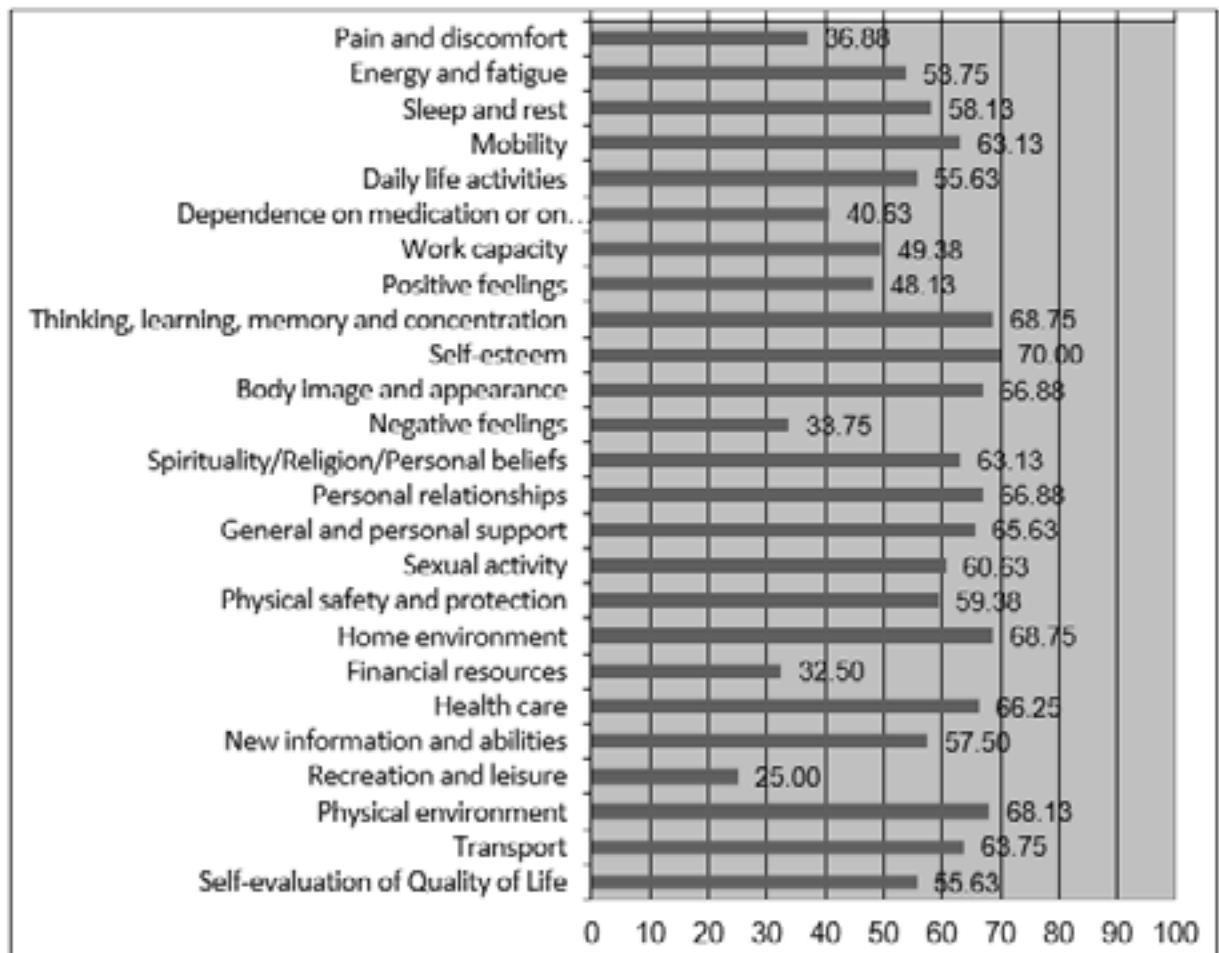


Figure 2 – Distribution of QoL mean values, according to facet distribution of the WHOQOL-BREF questionnaire. João Pessoa, PB, Brazil, 2018
Source: Own search.

DISCUSSION

The results show a sample with social and clinical characteristics of vulnerability, represented by low educational level, few financial resources and involvement in the most aggressive forms of the disease, which can lead to the onset of sequelae and negatively influence the QoL of individuals.

A study conducted in João Pessoa-PB points out that individuals with low education may have the ability to perform impaired preventive actions, if the guidelines related to the prevention and treatment of the disease are not understood correctly, making them more likely to develop sequelae.⁽¹³⁾

Regarding the financial situation, there is a wide literature that shows the low financial

power of leprosy patients.^(4,14-15) This situation can provide individuals with environmental conditions that favor the contagion and proliferation of the disease, given the possibility of living in precarious conditions of housing, hygiene and food.

Socioeconomic conditions, such as low schooling and family income, also imply difficulties in access to health, which, in turn, contribute to the permanence of individuals with contagious (multibacillary) forms, constituting themselves as determining factors for the maintenance of endemic.⁽¹⁶⁾

Regarding the involvement by the most severe forms, it is emphasized that the multibacillary individuals are the ones with the largest load of bacilli, besides having immunological instability against them, thus having a greater possibility of neural involvement and, consequently, the development of physical disabilities. A study conducted in an endemic city of Minas Gerais found that these individuals are nine times more likely to develop the disease's sequelae when compared to paucibacillary.⁽¹⁷⁾

It is important to highlight that, in addition to this social and clinical vulnerability, there are acute inflammatory complications caused by leprosy reactions that can cause damage to individuals in the physical, psychological, social and economic spheres due to alterations in sensory, motor, physical and autonomous functions.⁽⁴⁾

Concerning the analysis of the WHOQOL-BREF responses, in general the best QoL scores were found for the social relations domain and the lowest ones belonged to the physical domain, although all obtained scores above 50 points, and were therefore considered satisfactory.

In the investigation of the QoL of individuals with leprosy in the city of Minas Gerais, a similarity to the findings of this study is observed, emphasizing the importance of family support to deal with the disease in the social relations domain and attributing the manifestations of leprosy reactions, the physical disabilities and the drug side effects as complaints related to the physical domain.⁽¹⁸⁾

The first items of WHOQOL-BREF cover general aspects of QoL: Q1 (How do you rate your quality of life?) and Q2 (How satisfied are you with your health?), with 45% of the sample reporting good QoL and 52.5% high satisfaction with their health. These findings corroborate a study conducted at the Lauro de Souza Institute in Bauru-SP that found satisfactory results in these questions demonstrating satisfaction with health and, consequently, good QoL.⁽¹⁵⁾

In Q1, the subjective aspects of response among individuals are also worth mentioning since, although 45% reported QoL as good, 40% reported that it is neither good nor bad.

In the stratification of the domain questionnaire, in terms of the physical domain, the answers obtained in Q3 (How far do you think your (physical) pain prevents you from doing what you need?) stand out, where 50% of the respondents reported an extreme limitation to perform activities due to pain.

The QoL assessment study of leprosy patients also identified reports of many complaints of pain by patients, even with the presence of health staff available for treatment in loco.⁽¹⁹⁾

Among the main causes of pain in leprosy patients are those caused by neuropathies, which can manifest themselves acutely or chronically. Acute ones commonly occur in the course of reaction episodes and are characterized by the presence of intense pain that may occur spontaneously or due to hypersensitivity to palpation of nerve trunks, and chronic pain symptoms vary from insidiously onset and progressing from the beginning. slow form.⁽²⁰⁾

In addition to the physical domain, neuropathic pain may also be able to negatively influence the psychological and environmental domains, as it may cause deterioration of

the individual's functional capacity, making it difficult and/or unfeasible to perform the activities of daily living.⁽²¹⁾

Referring to the psychological domain through items Q6 (To what extent do you think your life has meaning?); Q7 (How much can you concentrate?); Q11 (Are you able to accept your physical appearance?); and Q19 (How satisfied are you with yourself?), there are high levels of satisfaction among the respondents, 77.5%, 77.5%, 67.5% and 70%, respectively, and it can be inferred that, despite the disease, they have good concentration and self-esteem, being satisfied with their body image and appearance.

Contradictorily, the answers to question 26 about the frequency of negative feelings deserve to be highlighted in this domain. Most of the participants (42.5%) reported the presence of feelings such as moodiness, despair, anxiety and depression.

The presence of these feelings may be related to the fact that leprosy reactions, when causing acute inflammatory complications in patients, such as new skin lesions, fever, pain and malaise, due to deregulation and exacerbation of the immune response to the bacillus, may lead patient to the thought that drug treatment is making it worse, causing fear and insecurity.^(4,22)

Concerning the social relations domain, individuals were asked about their personal relationships, sexual activity, and social support in questions Q20 (How satisfied are you with your personal relationships (friends, relatives, acquaintances, colleagues?)), Q21 (How satisfied are you with your sex life?) and Q22 (How satisfied are you with the support you receive from your friends?), respectively, with a high degree of satisfaction in the responses.

Ratifying these results, a study evaluated the social and intimate relationships of individuals with leprosy and found a satisfaction rate of 85% regarding social relations, 60% in their sexual life and 78.3% related to social support, reflecting on the importance of family and friendship relationships for coping with situations experienced by patients daily.⁽²²⁾

It is also possible to infer that, although the stereotyped conception of leprosy involving fears, taboos and prejudices is still present in the imagination of the population, in this study, this was not configured as an impeding factor for the social interaction of the patients.

In the environmental domain, the items related to financial condition and recreation were the ones that had the highest percentage of unsatisfactory answers, with 57% of the individuals reporting having no or few resources to meet their needs and 75% reporting having no or few leisure opportunities.

This dissatisfaction with the financial resources and leisure opportunities may reflect the disabling power of the disease, which may interfere with the daily activities and cause financial and social losses, impacting on family economic dynamics.⁽¹³⁾

Other authors have also reported high rates of unsatisfactory responses in these items.^(15,18-19) In this sense, it is essential to develop public policies related to health promotion aiming at reducing vulnerability situations, defending equity and incorporating social participation, thus positively affecting the psychic, social and cultural areas of leprosy patients.

These findings are limited to the reality of only one scenario, although it is believed to be like the Brazilian context. Thus, it is suggested to broaden the methodological scope in order to provide greater knowledge about the QoL of the patients undergoing leprosy reactions, so that better care strategies can be mapped or improved aiming at the well-being of this population.

CONCLUSION

The results indicate that individuals under treatment of reaction states have good QoL, although some aspects, notably related to pain and discomfort, medication dependence, work capacity, negative feelings, financial resources, recreation, and leisure, negatively influence their overall assessment.

Based on the findings, it is understood that the aspects related to the pathophysiology of reactions, living conditions and health policies influence the daily life of this population too much, reflecting on the public, political and social possibilities that can be achieved by the individuals when efforts are directed specifically to address them.

At this juncture, we highlight the importance of the presence of a trained multi-professional health team (mainly in the areas of nursing, physiotherapy, occupational therapy, medicine and psychology), with a view to acting through educational actions, physical therapies and approaches so that the negative aspects can be minimized, and the positive ones strengthened.

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