








QUALITY OF LIFE AND CLINICAL CONDITION OF INDIVIDUALS WITH LEPROSY

QUALIDADE DE VIDA E CONDIÇÃO CLÍNICA DE INDIVÍDUOS COM HANSENÍASE

CALIDAD DE VIDA Y ESTADO CLÍNICO DE LAS PERSONAS CON LEPROSA

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ABSTRACT

Objective: to analyze the quality of life of individuals with leprosy undergoing treatment in the Basic and Specialized Health Care network and to perform a comparison according to the clinical conditions of the patients. **Method:** cross-sectional, analytical study carried out in Primary and Specialized Health Care in João Pessoa, Paraíba, Brazil. The sample was collected between January and March 2017, consisting of 96 individuals undergoing treatment for the disease, aged over 18 years. Information was collected using a semi-structured form containing sociodemographic and clinical variables and the validated instrument World Health Organization Quality of Life Assessment brief. Data were analyzed based on descriptive analysis techniques, using the Normality (Kolmogorov-Smirnov), Levene, parametric t and ANOVA (post hoc Tukey test) tests. **Results:** the overall score for quality of life among the 96 research subjects remained intermediate (\bar{x} = 57.04), with the Physical domain being most negatively affected (\bar{x} = 54.09). The questions contained in the domains "recreation and leisure" (\bar{x} = 31.41), "negative feelings" (\bar{x} = 35.16), "Financial Resources" (\bar{x} = 35.68) and "Pain and distress" (\bar{x} = 35.68) had a lower mean score. Patients with clinical conditions "osteoporosis and arthritis" (p = 0.011) and "current neuritis" (p = 0.001) had an intermediate quality of life. **Conclusion:** it was shown that people with leprosy have an intermediate quality of life, especially when associated with neuritis and comorbidities, which highlights the need for continuous monitoring of research subjects.

Keywords: Leprosy; Quality of Life; Nursing; Neuritis; Osteoporosis; Osteoarthritis.

RESUMO

Objetivo: analisar a qualidade de vida dos indivíduos com hanseníase em tratamento na rede de Atenção Básica e Especializada de saúde e realizar uma comparação de acordo com as condições clínicas dos pacientes. **Método:** estudo transversal, de caráter analítico, realizado na Atenção Básica e Especializada de saúde em João Pessoa, Paraíba, Brasil. A amostra foi coletada entre os meses de janeiro e março de 2017, sendo composta por 96 indivíduos em tratamento para doença, na faixa etária acima de 18 anos de idade. As informações foram coletadas a partir de um formulário semiestruturado contendo variáveis sociodemográficas e clínicas e o instrumento validado World Health Organization Quality of Life Assessment brief. Os dados foram analisados com base nas técnicas de análise descritiva, tendo sido aplicados os testes de Normalidade (Kolmogorov-Smirnov), Levene, t paramétrico e ANOVA (teste post hoc tukey). **Resultados:** o escore geral para qualidade de vida entre os 96 participantes da pesquisa se manteve intermediário (\bar{x} = 57,04) sendo o domínio físico mais afetado negativamente (\bar{x} = 54,09). As questões contidas nos domínios "Recreação e lazer" (\bar{x} = 31,41), "Sentimentos negativos" (\bar{x} = 35,16), "Recursos Financeiros" (\bar{x} = 35,68) e "Dor e desconforto" (\bar{x} = 35,68) apresentaram menor escore médio. Pacientes com condições clínicas "osteoporoze e artrose" (p = 0,011) e "neurite atual" (p = 0,001) obtiveram qualidade de vida em nível intermediário. **Conclusão:** evidenciou-se que pessoas com hanseníase têm qualidade de vida em nível intermediário, principalmente quando associada à neurite e a comorbidades, o que ressalva a necessidade de acompanhamento contínuo dos participantes da pesquisa.

Palavras-chave: Hanseníase; Qualidade de vida; Enfermagem; Neurite; Osteoporoze; Osteoartrite.

RESUMEN

Objetivo: analizar la calidad de vida de los individuos con lepra en tratamiento en la red de Atención Primaria y Especializada y su comparación según las condiciones clínicas de los pacientes. **Método:** estudio transversal, de carácter analítico, realizado en la Asistencia Sanitaria Básica y Especializada de João Pessoa, Paraíba, Brasil. La muestra se recogió entre enero y marzo de 2017, formada por 96 individuos en tratamiento por la enfermedad, mayores de 18 años. La información se recogió mediante un formulario semiestructurado que contenía variables sociodemográficas y clínicas, y el instrumento validado World Health Organization Quality of Life Assessment brief. Los datos se analizaron a partir de las técnicas de análisis descriptivo y se aplicaron las pruebas de normalidad (Kolmogorov-Smirnov), Levene, t paramétrica y ANOVA (prueba de tukey post hoc). **Resultados:** la puntuación global de la calidad de vida entre los 96 participantes en la investigación se mantuvo en un nivel intermedio (\bar{x} = 57,04) y el dominio físico fue el más afectado negativamente (\bar{x} = 54,09). En cuanto a las preguntas contenidas en los dominios, "Recreación y ocio" (\bar{x} = 31,41), "Sentimientos negativos" (\bar{x} = 35,16), "Recursos económicos" (\bar{x} = 35,68) y "Dolor y malestar" (\bar{x} = 35,68) mostraron puntuaciones medias más bajas. Los pacientes con condiciones clínicas de "osteoporosis y artrosis" (p = 0,011) y "neuritis actual" (p = 0,001) obtuvieron una calidad de vida de nivel intermedio. **Conclusión:** se evidenció que las personas con lepra tienen un nivel intermedio de calidad de vida, especialmente cuando se asocia a neuritis y comorbilidades, lo que pone de manifiesto la necesidad de un seguimiento continuo de los participantes en la investigación.

Palabras clave: Lepra; Calidad de Vida; Enfermería; Neuritis; Osteoporosis; Osteoartritis.

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INTRODUCTION

Leprosy is an infectious disease with a chronic process and with a strong disabling power, being part of the group of ten Neglected Tropical Diseases (NTDs). Despite the global efforts outlined through global goals and specific strategies, the indicators of the disease still point to a path of perpetuation of morbidity. In the meantime, the most recent global strategy to fight leprosy changes its scope: before it was focused on its elimination as a public health problem; now, it focuses on interrupting transmission and achieving zero autochthonous cases.¹

Epidemiologically, the profile of the epidemic has changed-albeit slowly. In 2019, a total of 202,256 new cases of the disease were diagnosed in 118 countries (26 cases per million inhabitants). Of these, 96% were reported by the 23 global priority countries, with 79% in India, Brazil, and Indonesia. Sixty-six countries reported fewer than 100 cases. Of the cases with Grade 2 Disability (G2D), detected at the time of diagnosis, there were 10,816, which are mostly distributed in Southeast Asia, Africa, and the Americas (respectively).¹

With regard specifically to Brazil, in the last five years, 137,385 new cases of leprosy were reported. In 2020, there were 17,979 new cases, of which 1,504 with G2D. The detection of cases with Grade Disability 2 evidence the late diagnosis, due to the greater physical impairment caused by leprosy. In this sense, the indicator follows the trend of general case detection.²

Taking into account the Disability-adjusted life years (DALYs) indicator - which represents the years of healthy life lost, either due to disease mortality or the potential to generate disability - in 2016, in Brazil, the highest rates of DALYs were concentrated in individuals of more advanced age groups when affected by neglected tropical diseases, including leprosy. Due to immunosenescence, it is necessary to prioritize the longitudinal care of these individuals, in which a therapeutic relationship is expected that involves responsibility on the part of the healthcare professional and trust on the part of the user.³

The epidemiological power of leprosy reaches even more relevant social levels when one understands its disabling power. Physiologically, it is related to the ability of the bacillus to gradually affect Schwann cells, causing inflammatory processes and/or immune responses that, in turn, worsen the condition and directly affect the ability of affected individuals to respond to nervous, motor, sensory and/or autonomous.

The pathological cycle of leprosy involves primary and secondary lesions that vary in severity and generate deformities and disabilities, especially on the face, hands, and feet.⁴

That said, it is suggested (in the absence of verifiable data) that 3 to 4 million people live with visible physical disabilities due to leprosy, sufficient data alone to raise research on the subject.¹ However, adding potential, there is an association of the peculiarities of the disease with how the way of perceiving it is affected in the physical, emotional, social, cultural condition, among other aspects that reverberate in the quality of life of these individuals.

In approaches to Quality of Life (QoL), it is necessary to pay attention to the multiplicity of issues that involve this universe. There is no conceptual consensus on health related QoL. The QoL measurement instruments allow, from the individual perception, to bring information inherent to physical well-being, relationships with family and friends, financial conditions that guide issues related to housing, leisure, transportation, opportunities to acquire new information and skills, access to health services, education, spirituality, personal beliefs, well-being, and life satisfaction.⁵⁻⁷

For QoL, this study adopts the concept of the WHOQOL group, in which it is understood as “the individual’s perception of their position in life, in the context of their culture and in the system of values in which they live and in relation to others”. their expectations, their standards, and their concerns”.⁸

Consubstantiating such importance of leprosy in the social, economic, political and health context, there is the work performed by professionals from the Unified Health System (SUS, *Sistema Único de Saúde*), who develop care work full of edges, whether in Primary Care, gateway to entry to the entire healthcare network, whether in specialized care, referenced and counter-referencing care that must be comprehensive and for memorizing the perception of each individual about their process of illness, healing and/or adaptation to the new condition of life.⁹

The relationship between leprosy and quality of life has been the subject of studies that recognize this disease as a cause of suffering that goes beyond pain and discomfort strictly linked to physical damage, having a great social and psychological impact.^{10,11} However, the regional differences in Brazil support the need for research that point out how sociodemographic and clinical variables can help to understand the social determinants of health in this population.

Given the above, just treating the leprosy disease is not enough: it is necessary to consider the needs related to the QoL of individuals, given that physical disabilities, deformities and the stigma related to the disease restrict work and social activities, potentiate the imbalance the state of complete physical, mental and social well-being of those affected by the disease, compromising QoL.¹² Therefore, the objective of this study is to analyze the quality of life of individuals with leprosy undergoing treatment in the Primary and Specialized Health Care network and their comparison according to the clinical conditions of the patients.

METHOD

This is a cross-sectional, analytical study, carried out from January to March 2017, in Primary Care (in 19 Family Health Units distributed in 5 health districts) and in Specialized Health Care (Leprosy Dermatology Outpatient Clinic at Hospital de Infectious diseases Doutor Clementino Fraga Filho) in the city of *João Pessoa, Paraíba*, Brazil. In order to ensure the high-quality presentation of the present study, the guidelines of the Declaration of Strengthening the Report of Observational Studies in Epidemiology (STROBE) were used.¹³

To compose the sample, the following inclusion criteria were adopted: individuals over 18 years of age who were undergoing polychemotherapeutic treatment for leprosy and who had preserved cognition. The age group adopted was due to the fact that the exclusive care of adults in the hospital service occurs in the shift that the researchers had available to carry out the research. Individuals whose diagnosis had been confirmed for less than 30 days and/or who were being treated only leprosy reaction were excluded.

The eligible population consisted of 171 individuals registered in the dermatology service of the aforementioned hospital. Assuming a confidence level of 95% and based on a margin of error of 5%, an estimated sample of 84 individuals was obtained, 22 of them in Primary Care (sample carried out according to the allocation method proportional to the number of patients in the units per district) and 62 from Specialized Care. In view of the number of patients scheduled for consultation during the collection period, the sample was expanded for convenience, totaling 96 individuals.

For the operationalization of data collection, 4 participating researchers were needed, who were previously instructed through an expository and dialogic class on the pathophysiological and clinical aspects of leprosy, as well as on the objectives and applicability of the instruments of this research. It is noteworthy that the team in question was already involved in research involving the theme, as they constitute the research subgroup "HANSEN", which is part of the Research Group on Wound Treatment (GEPEFE, Grupo de Pesquisas em Tratamento de Feridas), linked to the Universidade Federal da Paraíba.

The interviews were carried out in loco (either in the referral hospital or in the basic health units), lasting approximately 20 minutes. For this, two collection forms were used: 1) semi-structured form containing sociodemographic variables (gender, age, marital status, number of children, education, family income and number of family members living in the same house) and clinics [operational classification - Paucibacillary (PB) and Multibacillary (MB), clinical form - indeterminate (PB), tuberculoid (PB), dimorphic (MB), virchowian (MB) -, bacilloscopy, Degree of Physical Disability - DPD at diagnosis, DPD at last evaluation, leprosy reaction, associated diseases - hypertension, diabetes mellitus, osteoporosis, arthrosis, plantar/palm ulcers and neuritis]; and 2) the World Health Organization Quality of life Assessment brief-WHO-QOL-brief form.

The latter is an instrument validated by the World Health Organization (WHO) to analyze the Quality of Life of study subjects. It consists of an abbreviated version of the WHOQOL 100, which can be used in research involving healthy individuals or those with chronic diseases, such as diabetes mellitus, leprosy, and others. The instrument consists of 26 questions, 2 of which are aimed at the perception of QoL and satisfaction with health, and 24 questions distributed in the physical, social, environmental, and psychological domains.¹⁴

Taking into account that the WHOQOL-brief instrument uses a Likert-type scale, it was decided to consider the subjects' response scores in the same modality, that is, divided and classified into quartiles. Thus, QoL results were classified into five categories: very poor QoL (score ranges from 0 to 24 points); poor QoL (score varies from 25 to 49 points); intermediate QoL (score varies from 50 to 74 points); good QoL (score ranges from 75 to 99 points); very good QoL (> 99 points).¹⁴

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 21.0 software, based on descriptive data analysis techniques. The following statistical tests were applied, at a 5% significance level: parametric t-test, for comparing the means of two independent samples, satisfying the Kolmogorov-Smirnov test for data normality; Levene test, to compare the equality of variance; ANOVA test, for comparison of several means and, in case of statistical significance, for “neuritis”, the Post Hoc Tukey test was used for ANOVA (showing significance for the groups “current neuritis” and “never had neuritis” with p value = $0.003 < \alpha = 0.01$).¹⁵

The missing data are justified by the lack of clinical information in the medical records of the research subjects, such as operational classification (2), leprosy reaction (1), neuritis (1), DPD at diagnosis (13), DPD from the last evaluation (12), plantar/palmar ulcer (1) and clinical form (9).

The study was approved by the Ethics Committee of the *Universidade Federal da Paraíba do Centro de Ciências da Saúde* through an addendum to a broader project developed in the Postgraduate Program in Nursing at the master’s level of the main author, under favorable Opinion Report No. 3,889,691 Study subjects were instructed, before signing the Free and Informed Consent Form, about voluntary participation, anonymity, and freedom to withdraw from the study at any time. The present research was carried out based on the ethical aspects in research involving human beings, recommended by Resolution No. 466/12 of the National Health Council.¹⁶

RESULTS

This research involved 96 individuals with leprosy. The analysis of the results showed that most individuals were male (55.20%), with an average age in the economically active range of 45.5 years, married (53.10%), with low educational level (54.20%) and income of one minimum wage (60.90%). With regard to the clinical characteristic of leprosy, we have multibacillary (85.40%), borderline form (45.80%). At diagnosis, 45.83% had DPD zero and 18.1% had DPD 2; 55.80% never had a leprosy reaction and 88.40% never had neuritis.

With regard to the investigation of the QoL of individuals with leprosy, it can be inferred, from the graph below, that the total mean of the global score is classified as intermediate. As for the domains present

in the WHOQOL-bref, the physical, psychological and the environment influenced the decrease in the average of the intermediate QoL, while the domain social relationships acted in the increase of the average of the intermediate QoL (Figure 1).

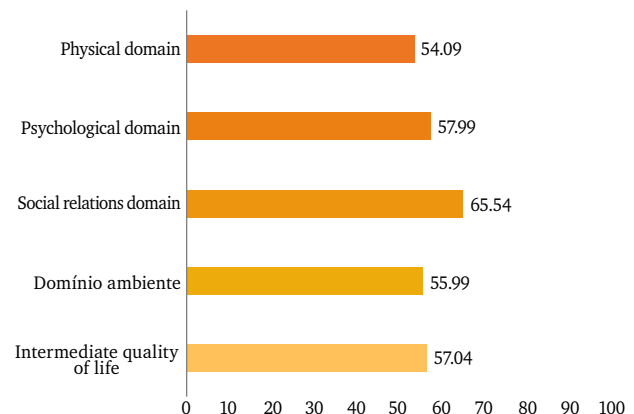


Figure 1 – Mean Quality of Life scores according to the domains of the WHOQOL-bref instrument of individuals with leprosy treated in the Primary and Specialized Health Care network. João Pessoa, Paraíba, Brazil, 2017

Source: Direct research, 2017.

In detail, the domains expressed by the WHOQOL - bref are composed of questions on which relevant aspects for QoL are found. The question “Recreation and leisure” ($\bar{x} = 31.41$), from the Environment domain; “Negative feelings” ($\bar{x} = 35.16$), linked to the psychological domain; “Financial Resources” ($\bar{x} = 35.68$), directed to the Environment domain; “Pain and distress” ($\bar{x} = 35.68$), related to the Physical domain, had a lower mean score, influencing the decrease in the mean for the domains to which they belong, as well as for the intermediate QoL.

The questions “self-esteem” ($\bar{x} = 68.23$), in the Psychological domain; “Personal support and Assistance” ($\bar{x} = 67.19$) and “Personal Relationships” ($\bar{x} = 66.93$), referring to the Personal Relations domain; and “Mobility” ($\bar{x} = 66.67$), belonging to the Physical domain, showed a higher mean score. Consequently, they influenced by increasing the mean of the domain to which they belong, as well as the intermediate QoL (Figure 2).

When comparing the mean score of the WHOQOL-bref with the clinical condition of individuals with leprosy, it was observed that those with osteoporosis and arthrosis ($p < 0.011$) and neuritis ($p < 0.001$) had a lower mean QoL compared to those without these conditions. conditions, osteoporosis, arthrosis ($\bar{x} = 78.4$) and with current neuritis ($\bar{x} = 66.6$) (Table 1).

Quality of life and clinical condition of individuals with leprosy

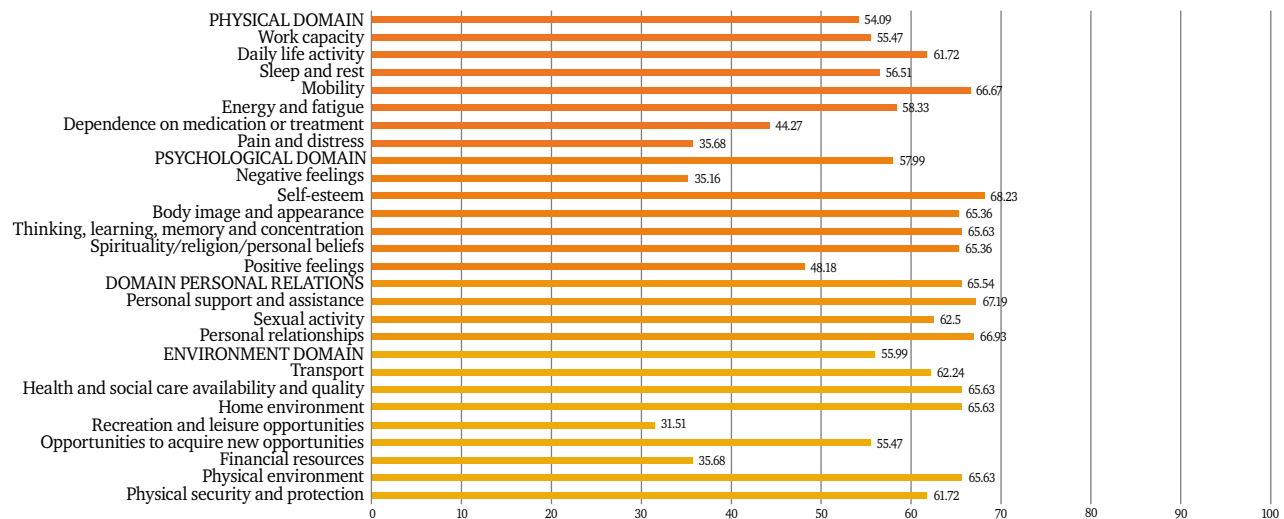


Figure 2 - Mean scores per question of the WHOQOL-bref instrument of individuals with leprosy treated in the Primary and Specialized Health Care network, João Pessoa, Paraíba, Brazil, 2017(em arquivo anexo)
Source: Direct research, 2017.

Table 2 - Comparison of the average WHOQOL-bref score according to the clinical conditions of individuals with leprosy treated in the Primary and Specialized Health Care network, João Pessoa, Paraíba, Brazil, 2017

Variables ^{(a),(b)}	n	%	Mean	Standard Deviation	p - value
Diabetes					
No	85	88.5	88.2	15.94	p = 0.380 ^(c)
Yes	11	11.5	83.8	11.09	
SAH					
No	81	84.4	89.0	14.88	p = 0.065 ^(c)
Yes	15	15.6	80.9	17.39	
Osteoporosis and Arthrosis					
No	81	84.4	89.4	15.51	p = 0.011 ^{*(c)}
Yes	15	15.6	78.4	11.83	
Plantar/palmar Ulcers					
Previous	5	5.3	78.2	20.4	p = 0.163 ^(c)
Never had	90	94.7	88.2	15.2	
Operational Classification					
Paucibacilar	12	12.8	80.4	15.44	p = 0.066 ^(c)
Multibacilar	82	87.2	89.1	14.96	
DPD in diagnosis					
DPD 0	44	53.0	90.9	13.20	p = 0.084 ^(d)
DPD 1	24	28.9	82.9	16.42	
DPD 2	15	18.1	90.1	14.19	
DPD of the last assessment					
DPD 0	45	53.6	90.7	15.10	p = 0.390 ^(d)
DPD 1	24	28.6	85.5	14.86	
DPD 2	15	17.9	88.7	13.79	
Clinical Form					
Indeterminate	5	5.7	82.6	7.77	p = 0.280 ^(d)
Tuberculoid	7	8.0	77.6	19.52	
Dimorphic	44	50.6	89.3	15.79	
Virchowiana	28	32.2	89.2	12.35	
Pure Neural	3	3.4	93.0	6.08	
Neuritis					
Current	7	7.4	66.6	21.35	p = 0.001 ^{** (d)}
Previous	4	4.2	85.8	21.08	
Never had	84	88.4	89.4	13.52	
Leprosy Reaction					
Type I	27	28.4	84.6	15.81	p = 0.477 ^(d)
Type II	11	11.6	86.3	14.36	
Have had at another time	4	4.2	87.0	14.58	
Never had	53	55.8	90.1	15.40	

(*) p-value < 0.05 and (**) p-value < 0.01. (+) Parametric t-test (c). (+) Anova parametric (d). Poc Hoc Tukey test for ANOVA. Degree of Physical Disability - DPD
Source: Direct survey, 2017

DISCUSSION

The sociodemographic profile (men, mean age 45.5 years, married, low education, income less than one minimum wage) and clinical characteristics (positive smear, multibacillary, borderline, DPD zero at diagnosis, never presented leprosy reaction, neuritis, plantar and palmar ulcers) of the subjects of the present study are similar to findings from research that address the same topic in Brazil.¹⁷⁻²⁴

Based on the WHOQOL-bref instrument, the assessment of QoL of the research subjects presented an intermediate general classification, with the physical, psychological and environment domains - especially the question "recreation and leisure opportunities" (\bar{x} =31.5) - influencing in the decrease of the average of the intermediate QoL, while the domain social relations collaborated for the increase of the general average of the QoL. The variables osteoporosis, arthrosis and current neuritis showed statistical significance related to intermediate QoL.

Similar to the findings of this research, a study carried out with patients who were discharged for leprosy cure in Natal-RN, Brazil, showed that the lowest QoL scores were found in cases where physical disability was present, with statistical significance for the physical, psychological and environment.⁶

With regard to the physical domain, the analysis of the questions, in isolation, suggests a negative influence of the aspects "Pain and distress" and "Dependence on medication or treatment" on this dimension. These results may be directly related to demyelinating neuropathy, which generates inflammatory processes recognized by episodes of intense acute pain (spontaneous or on palpation) and neural thickening. This is in line with a study carried out in the North region of Brazil, which, through the Visual Analogue Scale (VAS), classifies pain from moderate to severe in individuals with leprosy.²⁵ Pain can also affect the decrease in QoL of those affected by the disease.²⁶

In addition, in periods of manifestation of leprosy reactions, present in approximately 44.2% of the sample, the intensity of pain is aggravated by the exacerbated inflammatory reaction, which generates the need for, in addition to the use of single multidrug therapy (U-MDT), addition of analgesics and anti-inflammatory drugs for this new health condition, which contributes to drug dependence.²⁷ Other common problems, such as compressive syndromes, caused by compression and thickening due to edema of the nerves in the osteoligamentous channels (elbow regions, wrist, knee and ankle), cause pain, loss of strength, dysesthesia, impaired circulation and motor disorders.⁴

In this context, QoL is directly influenced by the inflammatory manifestations of leprosy, especially with regard to pain and distress.

The externalization of pain and neural involvement show that the disease still requires attention, aiming to prevent or minimize the progression of permanent neuronal injuries and disabling sequelae to reduce the impact on QoL. Neuropathic pain goes beyond the physical limits of the body, as it generates psychological impacts, damages daily life, interference in interpersonal relationships and a negative influence on QoL.²⁸

A study with a socio-anthropological approach analyzed the experience of women with leprosy reactions, and the aspect that stands out is pain management. When explaining their origin, reactions are placed in broader contexts and situations of stress or sadness. Research subjects demonstrate that having reactions is "worse" than having leprosy, as it is not always possible to predict or control them.²⁹ In accordance with this finding, one research that investigated QoL in elderly people with leprosy showed that pain, considered the fifth vital sign, prevented them from carrying out daily work activities.³⁰

The mean value of the question "Medication or Treatment Dependence" highlights the challenge of maintaining the treatment until the end of the standard regimen according to the patient's operational classification (paucibacillary 6 months and multibacillary 12 months), even in the face of possible side effects. It is inferred that the effects from multidrug therapy generate instability in QoL, which may be related to skin hyperpigmentation, gastritis, digestive disorders, nephrotic syndrome, hemolytic anemia, toxic hepatitis, among others.³¹ Another aspect of possible influence it is the prolonged submission of treatment of multibacillary cases (12 months), the majority present in this study (85.4%), becoming an obstacle for MDT adherence.⁴

Although the therapy is of great relevance to cure and interrupt the transmission chain of the bacillus, a study points out disadvantages that interfere with MDT adherence, such as: lack of patients' trust in the healthcare team, which is related to the credibility of the prescribed treatment by these professionals; difficulty for individuals of active ages to join the labor market, due to the objection of adapting to the schedule of health services; and the fact that patients who have already been cured have relapses.³¹

Regarding the Environment domain, in the questions about "Financial resources" and "Recreation and leisure", it is possible to observe low averages that distance the research subjects from the best QoL.

Based on the idea that having a higher education degree and working can indicate access to income, those individuals with lower professional qualifications are, therefore, poorly paid.³² In this sense, from the perspective of articulating some extra activity or means (pension for social security, retirement due to age or disability, government assistance, among others) that generate income for the individual with leprosy, reinforces the idea that the less favored, unemployment and the disabilities that this disease can generate and impact on activities affect various aspects of life. life, which deepens social difficulties, an aspect that requires attention from healthcare professionals.³²

Taking into account that 47% of respondents already have some degree of physical disability at the time of diagnosis, it is assumed that the patient may face difficulties in obtaining or maintaining a professional occupation, due to disabilities and deformities in body sites.³³ Thus, home providers are probably limited or unable to generate financial resources for the family, since, when the disease affects individuals of working age, related to low family income, it becomes a risk factor to health, because it motivates negative feelings (bad mood, depression, despair and anxiety), influencing the decrease in QoL.

Regarding the Psychological domain, the second worst average of all the instrument's questions is "Negative feelings", which strongly contribute to the decrease of the general average. These feelings are likely to be related to medication dependence due to other illnesses, prolonged MDT, or episodes of leprosy reaction (before, during and after MDT). Studies mention a worse perception of QoL because they associate the disease with negative feelings such as sadness (depression), in addition to the vulnerability of social isolation.^{34,35}

The subjects' low self-esteem may also be related to the feeling of shame, due to the bodily changes they undergo during the treatment of the disease, either by the thickening of the nerves that impair movements, or by the side effects of medications (especially Clofazimine, which alters the skin color), or even by leprosy reactions, which may manifest systemic signs, such as infiltration or the appearance of new spots and/or nodules. It is important to emphasize that patients who need psychological or psychiatric care should be referred for mental health follow-up in the basic unit or in a reference service.^{4,34}

With regard to the social domain, the questions with the highest percentage were "self-esteem", "assistance and social support", "personal relationships" and, finally, the question "mobility". Such points corroborated the increase in the general mean of QoL. Given the above, the results are unique, since the social history of the disease, as well as current national research, denote that individuals with leprosy are still victims of social exclusion, prejudice, and stigma, portraying the influence of leprosy on patients and pushing them away. of their common social activities and even of family members.^{36,37}

Moving on to a more comprehensive analysis, a comparison was made between the average scores of the WHOQOL-bref and the clinical condition of the research subjects, having identified the influence of osteoporosis and arthrosis on the decrease in the general score of QoL of the subjects of the present study. search. It is believed that the condition of accumulating several comorbidities potentiates the exacerbation of the pain of leprosy and increases the dependence on medications due to joint pain, swelling, stiffness, reduced joint mobility and loss of flexibility, compromising the performance of actions. activities of daily living or productive.^{38,39}

Keeping a focus on the influence of the clinical profile, the general mean of QoL among individuals who "never had neuritis" was 22.8 points above those who reported "current neuritis". Neuritis is characterized by the appearance of spontaneous pain (inflamed or swollen nerve) or compression of peripheral nerves (ulnar, fibular, posterior tibial, facial, and large auricular), with or without impairment of neurological function.³⁹ Primary nerve damage - neuritis - causes loss of sensory, motor, and autonomic functions, predisposing the individual to secondary injuries (traumatic, plantar ulcer, burns).⁴⁰

Initially, when the nerve is injured, the individual may experience onset or worsening of paresthesia complaints, numbness, and a burning sensation in body sites. Subsequently, neuropathy can cause irreversible damage, being often a disabling problem to perform simple work tasks, such as "cutting nails".⁴ These disabilities cause damage that extends to physical and psychological aspects, which are directly related to greater impairment of QoL.

Silent neuritis can also occur, in which nerve involvement can be triggered without pain or hypersensitivity to palpation, even in the presence of sensory and motor changes. Therefore, systematic, and periodic neurological assessment is necessary.

The extent and intensity of nerve damage, the degree of loss of sensation and paralysis depend on the clinical form of the disease, the duration of the reactional episodes and the age of the individual.⁴¹

Some aspects evaluated by the WHOQOL-bref are within the reach of actions of healthcare professionals in their clinical practice, such as: recognizing the psychosocial, economic, and biological needs of the individual; teach and encourage self-care, as well as participation in self-care groups to avoid disease sequelae; prevent the installation of disabilities; and implement individualized interventions with training for rehabilitation and design of assistive technologies.⁴²

Thus, it is relevant that these healthcare professionals adopt a posture that increases the visibility of the social, clinical, and psychological aspects, focusing on the prevention of disabilities to enable success in the QoL of the individual with leprosy. Therefore, the care model needs to go beyond the biomedical model when it comes to leprosy, due to the social problems that arise for the individual with the disease.

The Nursing team, as an agent of change, must identify vulnerabilities of the individual with leprosy, present intervention strategies and empower patients to perform their own act of care, promote the prevention of disabilities and health promotion and identify individual needs to prescribe the treatment. individualized plan of care. In this way, it is essential that Primary and Specialized Health Care professionals, through health education - a transforming care strategy -, adopt measures to promote, prevent and recover health to improve the QoL of patients and meet their biopsychosocial needs according to the individuality of each case, respecting the principles of equity and integrality of the Unified Health System in Brazil.

With regard to the limitations of the study, relevant clinical data on leprosy were probably not evaluated and/or considered by the healthcare professionals responsible for filling in the information in the patients' medical records, therefore, the study data was conditioned to these records, making it difficult to the realization of some inferences by the researchers.

As the instrument studied does not have a recommendation regarding the frequency of its use, it is necessary to carry out further research to better promote the feasibility of periodicity of use of the WHOQOL-bref in the clinical practice of healthcare services.

CONCLUSION

The study showed, through the WHOQOL-bref questionnaire, that individuals with leprosy undergoing treatment in the Primary and Specialized Health Care network had an intermediate QoL, and that the clinical profile of current neuritis, osteoporosis and arthrosis significantly influenced QoL.

The need to prioritize leprosy care as a chronic condition effectively inserted in the SUS care network is reinforced, as well as the recommendation to use the WHOQOL-bref as a routine in Primary and Specialized Care to promote quality action strategies for care. In addition, it is important to help tools so that Nursing professionals can be able to identify nuances of the disease, such as disabilities and physical deformities, identify factors that are interfering with QoL and guide patients on self-care practices on the face, hands, and feet to prevent secondary damage (fissures, ulcers, deformities) from trauma, abnormal pressure, and infections. Above all, the implementation of educational actions should be encouraged to promote adherence to self-care practices, as well as family and society awareness to support the prevention of disabilities.

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