



ORIGINAL

The quality of life of patients diagnosed with leprosy in a city in Piauí

Qualidade de vida de pacientes diagnosticados com hanseníase em um município do Piauí

Calidad de vida de pacientes diagnosticados con lepra en un municipio de Piauí

 Izabhel Chrystine Pereira de Souza¹
<https://orcid.org/0000-0003-2840-1247>

 Victorugo Guedes Alencar Correia¹
<https://orcid.org/0000-0003-2440-0343>

 Heidy Priscilla Velôso²
<https://orcid.org/0000-0002-0009-5519>

 Luís Evêncio da Luz¹
<https://orcid.org/0000-0003-2148-8175>

¹Federal University of Piauí, Teresina, Piauí, Brasil. ²São Paulo University (UNIP), Goiânia, Goiás, Brasil.

ABSTRACT

Objective: To analyze the domains of quality of life in patients with leprosy in a city of Piauí where the disease is highly endemic. **Methods:** This is a descriptive, cross-sectional study, carried out from February to November 2019. For data collection, a sociodemographic form and the SF-36 quality of life questionnaire were used. The information was analyzed using Mann-Whitney's U to compare the difference between two groups and the Kruskal-Wallis test, to compare the mean of two or more independent samples. **Results:** 46 patients participated in the study. When the socioeconomic and clinical variables related with the quality-of-life domains were evaluated, the "Emotional aspect" had the highest mean (78.25; sd: 39.88) while the lowest was found in the "Mental health" dimension (45.04; sd 24.95). The variable occupation had a negative relation with the general state of health ($p=0.002$) and mental health ($p=0.009$). **Conclusion:** Most dimensions evaluated presented a good score, indicating that the quality of life of the population studied was good. The exception were the dimensions "mental health" and "general state of health" when related with the variable occupation, whose score was low, indicating that the quality of life in these dimensions was low.

Descriptors: Quality of Life. Leprosy. Endemic Diseases.

RESUMO

Objetivo: analisar os domínios de qualidade de vida em pacientes com hanseníase em um município de alta endemicidade do Piauí. **Métodos:** trata-se de um estudo descritivo e transversal, realizado entre fevereiro e novembro de 2019. Para a coleta de dados, foram utilizados um formulário sociodemográfico e o questionário de qualidade de vida SF-36, sendo as informações analisadas por meio dos testes de U Mann-Whitney que visa comparar a diferença entre dois grupos e o de Kruskal-wallis que pretende comparar a média de duas ou mais amostras independentes. **Resultados:** participaram do estudo 46 pacientes. Quando avaliadas as variáveis socioeconômicas e clínicas relacionadas aos domínios de qualidade de vida, o "Aspecto emocional" obteve maior média (78,25; dp: 39,88) e a dimensão "Saúde mental" apresentou menor média (45,04; dp: 24,95). Já a variável ocupação relacionou-se negativamente com o estado geral de saúde ($p=0,002$) e saúde mental ($p=0,009$). **Conclusão:** a maior parte das dimensões avaliadas obteve boas pontuações, indicando uma boa qualidade de vida na população estudada, exceto as dimensões referentes a "saúde mental" e "estado geral de saúde" relacionados a variável ocupação, obtendo baixo score e indicando má qualidade de vida nesses últimos.

Descritores: Qualidade de Vida. Hanseníase. Doenças Endêmicas.

RESUMÉN

Objetivo: analizar los dominios de calidad de vida en pacientes con lepra en un municipio de alta endemia en Piauí. **Métodos:** estudio descriptivo y transversal, realizado entre febrero y noviembre de 2019. Para la recolección de datos, se utilizó una ficha sociodemográfica y el cuestionario de calidad de vida SF-36, siendo las informaciones analizadas a través de las pruebas U Mann-Whitney, que visan comparar la diferencia entre dos grupos, y el método de Kruskal-wallis, que compara la media de dos o más muestras independientes. **Resultados:** participaron del estudio 46 pacientes. Cuando evaluadas las variables socioeconómicas y clínicas relacionadas con los dominios de calidad de vida, el "Aspecto emocional" tuvo la media más alta (78,25; DE: 39,88) y la dimensión "Salud mental" tuvo la media más baja (45,04; DE: 24,95). La variable ocupación se relacionó negativamente con el estado de salud general ($p=0,002$) y la salud mental ($p=0,009$). **Conclusión:** la mayoría de las dimensiones evaluadas obtuvieron buenos puntajes, indicando una buena calidad de vida en la población estudiada, excepto las dimensiones referentes a "salud mental" y "estado general de salud", relacionadas con la variable ocupación, obteniendo un puntaje bajo e indicando mala calidad de vida en estos últimos.

Descriptores: Calidad de Vida. Lepra. Enfermedades Endémicas.

INTRODUCTION

According with literature, leprosy is an infectious disease caused by the bacillus *Micobacterium leprae*.⁽¹⁾ It is considered to be one of the oldest pathologies in the world and is associated with poor social and economic conditions.^(2,3) Its transmission takes place through prolonged contact with infected individuals and through droplets or aerosols.^(4,5) The diagnosis is clinical and epidemiological, and suspected lesions must be investigated through physical and dermatoneurological exams.⁽⁶⁾

Estimates show that nearly 27,000 new cases of leprosy are diagnosed every year in many low- and medium-income countries, meaning that the disease is a matter of public health.⁽⁷⁾ Moreover, there is a mean of 200,000 new diagnosis each year around the world, with more than 4 million people living with some sequela or disability caused by the disease.⁽⁸⁾

Brazil, India, and Indonesia are countries with a high incidence of cases, with the first occupying the second place in the world ranks.⁽⁹⁻¹⁰⁾ In 2017 alone, nearly 13% of the more than 200,000 cases in the world took place in the Brazilian territory.⁽¹¹⁾ From 2013 to 2017, the Northeast of Brazil registered the highest general number of notified cases of the disease.⁽¹²⁾

Due to its chronic nature, when leprosy is not treated properly, it can lead to the development of physical and psychosocial disabilities,⁽¹³⁾ in addition to the stigmatization of the patient.⁽¹⁴⁾ Therefore, it requires care that takes into consideration the principle of comprehensiveness, in addition to access to the many levels of health care.⁽¹³⁾

The medication treatment is carried out with antibiotics and called polychemotherapy (PCT). It aims to eliminate the bacteria from the body,⁽¹⁵⁾ and reduce the morbidity and mortality provoked by the pathology⁽¹⁶⁾ Even with the treatment, it has a strong impact in the life of the individual, resulting in physical, mental, and social discomfort and making daily life activities more challenging, which is made worse due to the social exclusion the patients are submitted to, all of which worsens their Quality of Life (QoL).^(17,18)

In regard to the QoL, many definitions can be associated with important principles, which are functional ability, socioeconomic power, satisfaction, emotional conditions, social interactions, intellectual activity, and health self-protection. Despite being a concept based on one's personal interpretation, people with leprosy have their QoL damaged as well.⁽¹⁹⁾ As a result, it is necessary to broaden the researchers that evaluate the QoL of this public, which would be essential to direct and carry out health policies.⁽²⁰⁾

In this context, considering the high number of diagnoses, their complexity, and the conditions that impact QoL, this research aims to analyze the QoL of individuals diagnosed with leprosy to ascertain these factors. This is justified by the need to increase the knowledge and the number of existing studies on the topic, so future actions to improve the QoL of those affected by the disease can be planned.

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Considering the above, our objective was to analyze the domains of QoL in patients with leprosy in a city of Piauí where the disease is highly endemic.

METHOD

This is a descriptive and cross-sectional study, carried out between February and November 2019, about the QoL of patients diagnosed with leprosy in the city of Picos-PI. The population of the study included 90 patients who received the diagnosis of the disease in Picos from 2015 to 2018 and were identified using records available in the Reference Center for the Treatment of Leprosy, which attends Picos and its neighboring cities, providing from diagnosis to the delivery of PCT.

For the selection of the sample, patients with a diagnosis of leprosy were included in the period mentioned above and registered in the reference center. Patients absent after three attempts of data collection were excluded (n=22), as well as those with invalid telephone information (n=15), minors (n=6), hospitalized patients (n=0), and those who passed away (n=1), to a total of 44 excluded patients. As a result, 46 were included.

Regarding data collection, after the identification of patients, the researchers invited them to go to the reference service. There, the goals of the research were explained and, after the participants agreed to participate and signed the Free and Informed Consent Form, data collection instruments were applied.

The instruments used were a sociodemographic form including the variables: sex, color, age group, marital status, income, educational level, profession, morbidities, practice of physical activity, and whether the patient used medication unrelated to the treatment of leprosy. The quality of life questionnaire SF36 was also applied, including 11 questions and 36 items (each with its respective value) in eight domains: functional capacity (ten items), physical aspects (four items), pain (two items), general state of health (five items), vigor (four items), social aspects (two items), emotional aspects (three items), mental health (five items), and a question comparing the participant's current perception of their health and their perception about their health one year prior. To interpret the answers, the numerical value of the answers was converted into a grade. The grades varied from 0 (zero) to 100 (one hundred), where 0 = the worst and 100 = the best result for each domain. This method is called Raw Scale, as the final value has no measuring unit. Using the final raw sale score, data were organized in tables and went through descriptive and inferential analyses carried out using the software Statistical Package for the Social Sciences (SPSS), version 20.0. After the tabulation of the data and the analysis of the results, the percentages from 0 to 100 were considered. the closest to 100%, the better the general QoL of the patient.

The descriptive statistics were analyzed through socioeconomic and clinical analysis, as well as the statistical inference. Mann-Whitney's U was used to compare between groups, and Kruskal-Wallis's test, which is used to compare the mean of two or more

independent samples, was applied. All tests considered $p < 0.05$ to be a significant difference with an interval of confidence of 95%.

This study was approved by the Research Ethics Committee of the Universidade Federal do Piauí (UFPI), Campus Senador Helvídio Nunes Barros (CSHNB), under opinion No. 3.342.232 and in accordance with all norms from Resolution No. 466, from December 12, 2012, for the development of researches with human beings.⁽²¹⁾

RESULTS

The sample included 46 patients with diagnosed leprosy. Most were female (58.7%), above 50 years old (52.2%), with incomplete elementary education (52.2%) and single (37.0%). Nearly 37.0% self-declared black and 58.7% declared to have an income below one minimum wage. Retirement pensions were the most common financial resource (37.0%) (TABLE 1).

Regarding the clinical variables studied using the sociodemographic form, most mentioned the presence of associated morbidities (76.1%), such as systemic arterial hypertension (SAH) (39.2%), Diabetes Mellitus (DM) (39.1%), the use of medication not associated with leprosy (69.6%), and 56.5% reported to be physically sedentary (TABLE 2).

Regarding statistical inferences, the eight domains of the instrument of QoL evaluation (SF-36) were associated with the sociodemographic and clinical variables of the participants (TABLE 3). The domain with the highest mean was Emotional Aspect (78.25; sd: 39.88), suggesting a positive dimension to the QoL of the person evaluated.

The mental health dimension, in turn, showed the lowest mean (45.04; sd: 24.95), being a negative factor in the evaluation of the QoL of the individuals evaluated. There was no significant association between any of the other domains, such as skin color and age group.

Still in regard to SF-36 dimensions and sociodemographic and clinical variables, Table 4 shows a significant association between educational level, profession, and morbidity, with $p = 0.021$, $p = 0.044$, and $p = 0.013$, respectively.

The Kruskal-Wallis test showed that the variable occupation had an effect over the following dimensions: general state of health ($p = 0.002$), social aspect ($p = 0.015$), and mental health ($p = 0.009$). The paired comparisons of the test mentioned showed the influence of the group that does not work/unemployed.

Then, the absolute and relative distribution of frequency of both sexes was carried out, according with their score in the questionnaire, which was classified as low, medium, or high for each domain. It is noteworthy that high scores were more common, for both sexes, in physical aspects, with the men scoring 16 (84.2%) and the women 19 (70.4%) in this domain. Emotional aspects were the second highest, with 15 (78.9%) and 19 (70.4%), respectively, showing a good QoL in these domains. In turn, for both sexes, low scores were most frequent in the mental health

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Also in Table 5, there was a comparison between the mean of the sexes and the total score of each SF-36 domain. The social aspect ($p = 0.023$) and mental health ($p = 0.018$) dimensions were influenced by sex.

Regarding the state of health of the participants of the study, when asked to compare their general state of health today with their state one year ago, 8 (13%) stated to be much better; 14 (31%) believed they are a little better; 11 (25%) declared to be about the same; 11 (25%) declared to be worse; and 2 (5%) stated to be much worse.

DISCUSSION

The results of this research found a higher number of female participants, disagreeing with a previous study that showed that most individuals with leprosy found in the database of the System of Notification of Information about Health Issues (SINAN), from 2013 to 2017, in three states in the Brazilian northeast, were male.⁽¹²⁾

Regarding their age group, a study carried out in public referral hospitals for the treatment of leprosy in João Pessoa found that most participants were older than 50 years of age, corroborating this research.⁽²²⁾

Regarding the clinical variable, a research showed similar results, indicating that participants were more commonly affected by SAH (56.3%) and DM (41.8%).⁽²³⁾ Literature reports that comorbidities may also be associated with the more advanced age group and result from aging, since elders tend to have other associated disease and a higher risk for complications.⁽²⁴⁾

In our study, there was a significant number of responses referring to other diseases, such as: arthrosis, arthritis, slipped disc, gastritis, depression, ankylosing spondylitis, and osteoporosis. The results of a previous study corroborate this work, as ti found that the high number of participants with comorbidities is a portrait of the lack of integral health care, one that is not focused on the treatment of a single disease, but on the attempt to provide therapies capable of anticipating diagnosis, favorilg QoL, and transforming the setting of leprosy in Brazil.⁽²⁵⁾

Regarding the domains of the QoL instrument, unlike in our research, a work carried out in São Luís-MA, presented a higher mean for mental health (64.38) and a lower one for physical aspects (20.0).⁽²⁶⁾ Another research found a higher mean for social aspects (73.6%).⁽²⁷⁾

A study discovered an unsatisfactory result for most participants regarding QoL and the domains analyzed, including those related with Mental health. 73.8% of patients with some form of mental disorder stated that they are using some form of psychoactive substance, showing that the prejudice they experience, associated with the stigma, the pain, and the disabilities provoked by the disease, justify the impact on their emotional and mental health.⁽²⁸⁾

Table 1. Numerical (n) and percentage (%) distribution of socioeconomic variables of people with leprosy (n=46). Picos-PI, Brazil, 2019

Variables		n	%
Sex	Male	19	41.3
	Female	27	58.7
Skin color	White	14	30.4
	Black	17	37.0
	Brown	15	32.6
Age group	18-29 years old	6	13.0
	30-39 years old	6	13.0
	40-49 years old	10	21.7
	50 years old or older	24	52.2
Marital Status	Single	17	37.0
	Married	14	30.4
	Divorced	3	6.5
	Widow/widower	12	26.1
Family income	< 1 minimum wage	11	23.9
	1 minimum wage	27	58.7
	2 minimum wages	7	15.2
	+ 2 minimum wages	1	2.2
Years of formal education	Illiterate	9	19.6
	Incomplete elementary school	24	52.2
	Complete elementary school	12	26.1
	Incomplete high school	1	2.2
Profession	Studies	3	6.5
	Works	16	34.8
	Does not work/unemployed	10	21.7
	Retired	17	37.0

Source: Research Data, 2019.
*minimum wage in 2019 (R\$ 954)

Table 2. Numerical (n) and percentage (%) distribution of clinical variables of people with leprosy (n=46). Picos-PI, Brazil, 2019

Variables		n	%
Morbidities	Yes	35	76.1
	No	11	23.9
Which morbidity?	SAH	18	39.2
	DM	10	21.7
	Cardiac diseases	2	4.3
	Other	18	39.1
Physical activity	Yes	20	43.5
	No	26	56.5
Uses medication unrelated with leprosy?	Yes	32	69.6
	No	14	30.4

Source: Research Data, 2019.

Table 3. Association between the score of the SF-36 domains and the sociodemographic variables of people with leprosy (n=46). Picos-PI, Brazil, 2019

Domains	Meand (sd)	Variables and significance levels (p-value) *		
		Color	Age group	Income
FC	63.37 (±35.15)	0.585	0.383	0.466
PA	77.17 (± 39.73)	0.662	0.739	0.158
P	54.52 (±38.29)	0.711	0.632	0.873
GHS	45.58 (±21.19)	0.508	0.811	0.159
V	62.95 (±22.47)	0.919	0.563	0.475
SA	73.29 (±30.65)	0.516	0.952	0.317
EA	78.25 (±39.88)	0.411	0.905	0.457
MH	45.04 (±24.95)	0.402	0.628	0.049

Source: research data, 2019*Kruskal-Wallis's test
Caption: FC = functional capacity; V = vigor; PA = physical aspect; SA = social aspect; P = pain; EA = emotional aspect; GSH = general state of health; MH = mental health

Table 4 Association between the score of the SF-36 domains and the socioeconomic and clinical variables of people with leprosy (n=46). Picos-PI, Brazil, 2019

Domains	Variables and significance levels (p-value)
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	Educational level*	Profession*	Morbidity**	Physical activity**
FC	0.021	0.044	0.013	0.813
PA	0.588	0.288	0.097	0.634
P	0.854	0.267	0.774	0.804
GHS	0.143	0.002	0.928	0.131
V	0.655	0.221	0.745	0.754
SA	0.337	0.015	0.502	0.371
EA	0.513	0.461	0.164	0.784
MH	0.510	0.009	0.736	0.894

Source: research data, 2019 *Kruskal-Wallis's test **Mann-Whitney's U test
Caption: FC = functional capacity; V = vigor; PA = physical aspect; SA = social aspect; P = pain; EA = emotional aspect; GSH = general state of health; MH = mental health

Table 5: Association between the score of the domains of SF-36 according with the sex of individuals with leprosy (n=46). Picos-PI, Brazil, 2019

Score of SF-36 dimensions*	Male		Female		p-value**
	n	%	n	%	
FC					0,280
Low	7	37.0	10	37.0	
Mean	2	10.6	5	18.5	
High	10	52.7	12	44.4	
PA					0.331
Low	3	15.8	7	25.9	
Mean	-	-	1	3.7	
High	16	84.2	19	70.4	
P					0.383
Low	7	37.0	11	44.4	
Mean	6	31.6	6	22.2	
High	6	31.6	9	33.3	
GHS					0.354
Low	7	37.1	15	55.5	
Mean	9	47.3	9	33.3	
High	3	15.8	2	7.4	
V					0.232
Low	3	15.8	7	25.9	
Mean	7	36.9	10	37.0	
High	9	47.5	10	37.0	
SA					0.023
Low	2	10.6	7	25.9	
Mean	3	15.8	8	29.6	
High	14	73.7	12	44.4	
EA					0.522
Low	3	15.8	6	22.2	
Mean	1	5.3	2	7.4	
High	15	78.9	19	70.4	
MH					0.018
Low	8	42.3	18	66.6	
Mean	5	26.4	6	22.2	
High	6	31.6	3	11.1	

Source: Research Data, 2019 *
Scores classified according with * Mann-Whitney's U test
*Low score: (0-49); Medium score: (50-74); High score: (75-100)
Caption: FC = functional capacity; V = vigor; PA = physical aspect; SA = social aspect; P = pain; EA = emotional aspect; GSH = general state of health; MH = mental health

Leprosy has strong psychological impact on the individuals, especially due to the stigma the disease brings with it, which often leads them to hide it, as they are afflicted by fear, shame, sadness, and anxiety, becoming more distant from the health service and with serious repercussions regarding the QoL.⁽²⁹⁾

The item functional capacity, in this work, was the most influenced by the variables, suggesting that

it has a close connection with the disadvantages of leprosy, which can be clinical and/or, mainly, sociodemographic.

The person affected by leprosy can develop physical disabilities due to changes in their sensitivity, which often cause damage that is difficult to fix. The bacillus *M. leprae* attacks the fibers of the peripheral nervous system, leading to sensory, motor, and autonomous changes and making it more

difficult for patients to protect themselves. This can lead to physical inability, often in the face, hands, or feet.⁽³⁰⁾

According with literature, the reduction of the functional capacity provoked by the disease, coupled with other factors, such as environmental, socioeconomic, and psychological ones, can directly impact the QoL of the person with leprosy, with negative repercussions on their routine instrumental daily life activities.⁽¹⁹⁾

Another study, similar to the one presented here, showed an influence of the variable sex on the mental health domain ($p=0.029$), with a higher value among women, due to the fact that men, despite being more affected by leprosy, deal better with problems associated with anxiety, depression, and emotional control than women; the dimension "social aspect", on the other hand, had no correlation with this item.⁽²²⁾

Literature highlights that the women with leprosy has a particular difficulty associated with gender, due to the fact that the weaknesses generated by the disease affect their ability to perform the socially pre-established roles they are expected to adhere to.⁽³¹⁾

The interference of leprosy in the life of women is related to their bodies, which are already socially modeled in their relation with domestic work and their livelihood, since the condition of women in our patriarchal society is superposed with certain aspects of the history of leprosy and the prejudice associated with it.^(32,33)

A limitation of this work includes the scarcity of studies that use the SF-36 to analyze leprosy, and which discuss question two in isolation - that is, the question referring to the comparison of the current health state with that of one year prior. This made it impossible to compare the analysis of the results found in this research with results from other investigations. Although the SF-36 is commonly employed for many maladies, it has been seldom used to study QoL associated with leprosy.

More investment is needed in future research that proposes instruments validated as to contemplate information about both general domains and specific domains, directed for each population. We also suggest the development of more studies with a qualitative approach or mixed methods.

As a result, this research is expected to contribute to increase the knowledge about the factors that influence the QoL of these patients, and to arouse the interest in carrying out further studies about the topic, thus aiding in the planning and development of actions targeted at improving the QoL of individuals with leprosy.

CONCLUSION

It was possible to determine that, in most dimensions evaluated, a good score suggested a good QoL, with the lowest scores in the items mental health and general health state, showing that the QoL in these aspects was low.

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Leprosy is a complex disease associated with a historic stigma, and these elements make it hard to provide early diagnoses or to have a prognostic free of sequelae. Therefore, it is extremely important to carry out new researches on the topic, to strengthen the measures for dealing with the disease, to look more carefully at this public, and to improve the attention provided to patients and their QoL.

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Corresponding author:

Izabhel Chrystine Pereira de Souza

Email: izabhels2@hotmail.com

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