








## ORIGINAL ARTICLE

## QUALITY OF LIFE, FUNCTIONALITY, AND SELF-CONCEPT OF PEOPLE POST-DISCHARGE FROM LEPROSY\*

### HIGHLIGHTS

1. Impairment of health-related quality of life.
2. Limited functionality and high self-concept.
3. Proposes actions aimed at preventing disabilities and/or deformities.
4. Qualify actions from a comprehensive and longitudinal care perspective.

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### ABSTRACT

**Objective:** to evaluate the quality of life, functionality, and self-concept of people after discharge from leprosy. **Methods:** This was a cross-sectional epidemiological study carried out in a reference institution for leprosy in Paraíba, Brazil, from May to August 2021. Four instruments were used for sociodemographic and clinical characterization, assessment of quality of life, functionality, and self-concept. The data was analyzed using Pearson's chi-square, Fisher's exact, Mann-Whitney, and Kruskal-Wallis tests. **Results:** 131 people took part, of whom 86 (65.6%) were male and 72 (55%) were aged between 41 and 60. There was a negative impact on health-related quality of life among those with no schooling and low family income. Limitation of functionality in those who do not practice physical activity, are affected by neuritis, and have some degree of physical disability. However, high self-concept. **Conclusion:** It is essential to train professionals and organize assistance measures in the face of longitudinal and interdisciplinary care in this therapeutic phase.

**DESCRIPTORS:** Quality of life; Disabled Persons; Self-Concept; Leprosy; Patient discharge.

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## INTRODUCTION

Leprosy is a chronic, infectious, and transmissible disease that affects the skin and peripheral nerves. When left untreated, it can cause permanent damage such as physical disabilities, deformities, and social exclusion. Classified by the World Health Organization (WHO) as a neglected tropical disease, its occurrence is commonly associated with the poor socio-economic conditions of a population. Stigma and discrimination have played an important role in social exclusion and the omission of rights for these people. In this sense, endemic countries such as Brazil, based on the proposals of the Global Leprosy Strategy 2021–2030, seek to achieve a world with zero Leprosy, zero disability, stigma, and discrimination<sup>1-2</sup>.

Health authorities are warning of delays in notifications, justified by the panorama of the COVID-19 pandemic that has ravaged the entire world. Thus, reflecting operational factors and not an epidemiological trend, preliminary data released by the Notifiable Diseases Information System (SINAN) showed a decline in the number of leprosy cases diagnosed in 2022. Only 14,962 new cases were registered nationwide, of which 5,490 have already been diagnosed with some degree of physical disability<sup>3</sup>.

Addressing the epidemiological scenario is necessary to understand the magnitude of the disease and the impact it has on the health status and quality of life of people affected by leprosy. Health indicators for this population can support the planning of public policy strategies with proposals based on targets for preventing disability<sup>4</sup>.

The concept of quality of life encompasses a subjective perception in the context of life, culture, and values about the goals, expectations, standards, and concerns of individuals or groups. When considering the high incapacitating potential of leprosy, studies show associated factors with a significant impact on health-related quality of life. These aspects increase the demand for rehabilitative therapy in specialized services<sup>5-7</sup>.

From this perspective, studies point to the low quality of life of people affected by leprosy after discharge from hospital after being healed<sup>8-9</sup>, especially in Brazil. However, there is a gap in the knowledge regarding the evaluation of aspects of health-related quality of life associated with functional issues and self-perception in this population.

It is important to enable health professionals, especially nurses, to plan comprehensive, longitudinal, qualified, humanized, and innovative care, with a focus on preventing the problems resulting from this condition. This study aimed to assess the quality of life, functionality, and self-concept of people after discharge from leprosy.

## METHOD

This is a cross-sectional epidemiological study, developed by the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). It was carried out at the dermatology outpatient clinic of the reference hospital for leprosy treatment, located in the municipality of João Pessoa, Paraíba. Data collection took place between May and August 2021.

The sample was non-probabilistic and the following inclusion criteria were used to select the participants: being over 18 years of age; having a diagnosis of leprosy and having completed the treatment regimen with multidrug therapy, regardless of the time of completion and the operational classification Paucibacillary or Multibacillary; and, as exclusion criteria: having a neurological, cognitive or psychiatric disorder that made it impossible to answer the items on the instruments accurately.

The restrictions imposed by the pandemic, users' access to health services, the criteria established for selecting the sample, and the deadline set in the schedule for face-to-face data collection all contributed to limiting the sample to 131 participants. This may characterize a possible sampling trend, as it does not represent the entire population served by the service.

Due to inconsistencies in the data provided by the institution, it was not possible to carry out an initial calculation to determine the sample size. Therefore, participants were selected because of convenience, according to the order in which they arrived at the outpatient clinic for a specialist consultation, as previously scheduled by the service. After the researcher had identified the eligibility criteria relevant to the selection, the participant was approached through a personal introduction and an invitation to take part in the study, informing them of the research design.

Due to the health restrictions imposed by the COVID-19 pandemic, data collection was carried out solely by the main researcher, in the outpatient waiting room of the service, in a reserved environment. Initially, a pilot test was carried out with five participants, which led to adjustments in the sociodemographic and clinical characterization instrument. After this stage, the interviews with the selected participants began, with four instruments being applied, lasting an average of thirty minutes, with only one meeting being sufficient for the participant to fill in the information; consultation of the patient's medical records, as a secondary source of information, took place after the interviews, when necessary.

The first instrument, designed by the researcher, was made up of questions related to the following: sociodemographic characterizations (gender, age group, marital status, schooling, family income, consumption of alcohol and/or cigarettes, and physical activity); and clinical operational classification treated, time of discharge from treatment, presence of leprosy reaction, neuritis and skin lesion, degree of physical disability, being of the structured type and made up of objective questions; the others integrated scales for assessing Health-Related Quality of Life (HRQoL), functionality and self-concept.

To assess the participants' WHOQOL-bref, the WHO-developed WHOQOL-bref (World Health Organization Quality of Life) instrument was used. The version contains adequate psychometric evidence and is made up of 26 facets, with Likert-type answers, in which it is possible to describe an individual's subjective perception of their physical and psychological health, social relationships, and the environment in which they live and how they feel over the last two weeks. There is no recommended cut-off point in the instrument's syntax, however, for this study, we adopted the suggestion of a cut-off point  $\geq 60$  for a better WHOQOL -bref, based on a cohort study on quality of life in the elderly<sup>10-12</sup>.

The Screening of Activity Limitation and Safety Awareness (SALSA) was developed and validated by a group of international collaborators, including Brazilians, based on the International Classification of Functioning, Disability and Health. It is recommended by the Ministry of Health, as it demonstrates adequate psychometric properties for use in people affected by leprosy and in post-discharge follow-up. According to its syntax, the score ranges from 0 to 80 and the degrees of limitation are classified as: no limitation (up to 24), mild limitation (25 to 39), moderate limitation (40 to 49), severe limitation (50 to 59) and extreme limitation (60 to 80). Therefore, the higher the score, the greater the functional limitation<sup>13</sup>. When associating these scores with sociodemographic and clinical variables, it was necessary to categorize them for better interpretation.

The Rosenberg Self-esteem Scale (UNIFESP-EPM/Rosenberg version), a generic public domain instrument with adequate psychometric properties (reproducibility, validity, and responsiveness), translated, validated, and cross-culturally adapted to the Brazilian context by Dini, Quaresma, and Ferreira (2004), was used to verify the participant's level of self-conception. Used in clinical practice and scientific research, the instrument includes subjective questions related to self-perception and personal self-assessment of ability, satisfaction, usefulness, quality, failure, and attitude. Composed of ten items, the answers follow a Likert-type scale, with a weight of zero to three and the results can vary from 0 to

30. There is no recommended cut-off point for the instrument's construct; however, for a two-dimensional analysis of the individual's positive and negative self-image, a score of 15 was adopted as the cut-off point. Thus, values  $\leq 15$  indicate high self-conception, and  $> 15$ , low self-conception<sup>14-15</sup>.

The data collected was tabulated and systematized in an Excell® spreadsheet through double typing, then submitted to quantitative descriptive statistical analysis where it was possible to characterize the sample in terms of the variables. For the results, only the variables with significant associations were considered.

The distributions of the data used in the study were analyzed using the Statistical Package for the Social Science (SPSS) for Windows, version 21.0. For statistical association, Pearson's chi-square and Fisher's exact non-parametric tests were used to determine whether two categorical variables are associated with each other; Mann-Whitney to check whether there is a statistically significant comparison when there is no homogeneity of variances; and Kruskal-Wallis when comparing three or more categorical variables, considering a significance level of 5%<sup>16</sup>.

The study was approved by the Research Ethics Committee (CEP) of the Lauro Wanderley University Hospital, linked to the Federal University of Paraíba, under opinion no. 4.663.032, in 2021.

## RESULTS

The study sample consisted of 131 participants, predominantly 86 (65.6%) male, 72 (55%) aged between 41 and 60, 67 (51.1%) married or in a stable union, and 74 (56.5%) with primary education. A total of 52 (39.7%) people received a pension or disability benefit (sickness benefit) and 89 (67.9%) only had a monthly minimum wage. Many participants, 102 (77.9%), denied drinking alcohol and/or smoking cigarettes and 87 (66.4%) did not practice physical activity.

As for the clinical profile, the multibacillary form was prevalent in 125 (95.4%) of the cases, and in two-thirds of the interviewees, 89 (67.9%) had been discharged from the MDT regimen for up to five years. At the time of the interview, 97 (74%) had a leprosy reaction, and 103 (78.6%) had developed some degree of physical disability. Neuritis affected 84 of the interviewees (64.1%), and 95 (72.5%) did not have any type of skin lesion.

Regarding the assessment of the participant's subjective perception of their WHOQOL-bref, according to the average scores obtained, there was significant impairment in the physical domain, which was the most affected, followed by the environmental and psychological domains. There was no impairment in the social domain.

There was a significant association between WHOQOL-bref and some sociodemographic variables, especially in the physical domain with gender, level of education, and family income, showing greater impairment in men, people with no schooling, and family income between 1 and 3 minimum wages since the p-values were less than the 5% significance level. The psychological and social domains were not statistically significant concerning the variables, as shown in Table 1.

**Table 1** - Association between health-related quality of life and sociodemographic and clinical variables of people post-discharge from leprosy cure (n=131), João Pessoa, PB, Brazil, 2021.

Variables	Domain 1 Physical		Domain 2 Psychological		Domain 3 Social		Domain 4 Environmental	
	average	p-value	average	p-value	average	p-value	average	p-value
<b>Gender</b>								
Female	0.49	0.028 <sup>‡</sup>	0.76	0.477 <sup>†</sup>	1.13	0.134 <sup>‡</sup>	0.76	0.999 <sup>‡</sup>
Male	0.73		0.86		1.45		0.78	
<b>Education level</b>								
No education	1.00	0.035 <sup>‡</sup>	1.06	0.115 <sup>‡</sup>	1.76	0.405 <sup>‡</sup>	0.94	0.148 <sup>‡</sup>
Elementary school	0.61		0.80		1.28		0.69	
High School	0.41		0.78		1.03		0.86	
Higher education	0.50		0.75		1.25		0.75	
<b>Family income</b>								
Up to 1 MW*	0.58	0.043 <sup>‡</sup>	0.81	0.977 <sup>‡</sup>	1.30	0.808 <sup>‡</sup>	0.74	0.735 <sup>‡</sup>
Between 1 and 3 MW*	0.83		0.86		1.47		0.83	
Above 3 MW*	0.50		0.83		1.17		0.83	

\*Minimum wage in force in 2021 (R\$1,100.00); †p-value obtained using Pearson's chi-squared test; ‡p-value obtained using Fisher's exact test.

Source: The authors (2021).

When questions were asked about functional limitations related to activities of daily living among those surveyed, it was observed that a significant majority of 113 (86.3%) had some type of limitation, classified as 41 (31.4%) mild limitation; 29 (22.1%) moderate limitation; 27 (20.6%) severe limitation and 16 (12.2%) very severe limitation.

According to the sample data, when functionality was associated with sociodemographic and clinical variables, the following were found participants with mild to moderate functional limitations, mainly men aged between 41 and 60, with a family income of up to 1 minimum wage, who did not practice any type of physical activity, affected by neuritis and with some degree of physical disability, as shown in Table 2.

**Table 2** - Association between functionality and sociodemographic and clinical variables of people post-discharge from leprosy cure (n=131), João Pessoa, PB, Brazil, 2021.

Variables	Categorized scores - SALSA						Categorized scores - SALSA
	No limitations		Light/Moderate		Severe/Very Severe		
	n	%	n	%	n	%	
<b>Gender</b>							
Female	1	5.6	27	38.6	17	39.5	0.021 <sup>†</sup>
Male	17	94.4	43	61.4	26	60.5	

<b>Age range</b>							0.002 <sup>‡</sup>
18 to 40 years old	11	61.1	24	34.3	6	14.0	
41 to 60 years old	4	22.2	36	51.4	32	74.4	
61 years or older	3	16.7	10	14.3	5	11.6	
<b>Family income</b>							0.028 <sup>‡</sup>
Up to 1 MW*	9	10.1	44	49.4	36	40.4	
Between 1 and 3 MW*	7	19.4	22	61.1	7	19.4	
Above 3 MW*	2	33.3	4	66.7	-	-	
<b>Physical activity</b>							0.014 <sup>‡</sup>
Walking	4	12.9	19	61.3	8	25.8	
Cycling	-	-	4	50.0	4	50.0	
Other	4	80.0	0	0	1	20.0	
No activity	10	11.5	47	54.0	30	34.5	
<b>Neuritis</b>							0.008 <sup>‡</sup>
No	7	43.8	22	34.9	4	10.5	
Yes	9	56.3	41	65.1	34	89.5	
<b>GIF**</b>							0.001 <sup>†</sup>
No	6	33.3	16	23.5	-	-	
Yes	12	66.7	52	76.5	41	100	

\*Minimum wage in force in 2021 (R\$1,100.00); \*\*Degree of Physical Disability; †p-value obtained using Pearson's chi-squared test; ‡p-value obtained using Fisher's exact test.

Source: The authors (2021).

As for the level of self-esteem, there was a significant majority of 111 (84.7%) participants with high self-concept.

Regarding the association between the level of self-esteem and the sociodemographic and clinical variables, the tests revealed that there was a significant association between the independent variables: gender, alcohol and/or cigarette consumption, family income, and the presence of neuritis in the participants. Therefore, men who do not consume any alcohol and/or cigarettes, with low family income, even when affected by neuritis, have high self-conception, as shown in Table 3.

**Table 3** - Association between self-esteem and sociodemographic and clinical variables of people post-discharge from leprosy cure (n=131), João Pessoa, PB, Brazil, 2021

Variables	Scores of The Rosenberg Self-Esteem Scale (UNIFESP-EPM/Rosenberg version)				p-value
	High self-esteem		Low self-esteem		
	n	%	n	%	
<b>Gender</b>					
Female	32	28.8	13	65.0	0.003 <sup>†</sup>
Male	79	71.2	7	35.0	

Use of alcoholic beverages/cigarettes					
Alcoholism	11	9.9	3	15.0	0.030 <sup>‡</sup>
Smoking	6	5.4	5	25.0	
Both	4	3.6	-	-	
None	90	81.1	12	60.0	
Family income					
Up to 1 MW*	70	78.3	19	21.3	0.017 <sup>‡</sup>
Between 1 and 3 MW*	35	97.2	1	2.8	
Above 3 MW*	6	100	-	-	
Neuritis					
No	32	32.0	1	5.9	0.038 <sup>‡</sup>
Yes	68	68.0	16	94.1	

\*Minimum wage in force in 2021 (R\$1,100.00); † p-value obtained using Pearson's chi-squared test; ‡ p-value obtained using Fisher's exact test.

Source: The authors (2021).

When the WHOQOL-bref and functionality scale scores were compared according to categorized variables, there was a significant difference in the physical, psychological, and environmental domains. Thus, for these domains, there was a directly proportional relationship between WHOQOL-bref impairment and functional limitations.

When comparing WHOQOL-bref scores and levels of self-esteem, a significant difference was found in all domains. Thus, it was found that people with high self-esteem have a better perception of WHOQOL-bref in all the domains investigated, as described in Table 4.

**Table 4** - Comparison between health-related quality of life, functionality and self-esteem of people post-discharge from leprosy cure (n=131), João Pessoa, PB, Brazil, 2021

Whoqol-bref	Domain 1 Physical (average)	Domain 2 Psychological (average)	Domain 3 Social (average)	Domain 4 Environmental (average)
<b>SALSA</b>				
No limitation	13.71	13.96	15.11	13.88
Mild/moderate limitation*	12.35	12.93	14.32	12.62
Severe/very severe limitation*	11.50	12.18	13.58	11.80
p-value	<0.001 <sup>†</sup>	0.004 <sup>†</sup>	0.120 <sup>†</sup>	0.001 <sup>†</sup>
<b>SELF-ESTEEM</b>				
High self-esteem	12.53	13.17	14.51	12.81
Low self-esteem	10.77	10.90	12.40	10.92
p-value	<0.001 <sup>‡</sup>	<0.001 <sup>‡</sup>	0.001 <sup>‡</sup>	<0.001 <sup>‡</sup>

\*Categorized variables from the SALSA instrument; †Kruskal Wallis test; ‡Mann-Whitney test

Source: The authors (2021).

## DISCUSSION

The socio-demographic profile found in the study corroborates the findings of other studies, with a predominance of male participants, aged between 41 and 60, corresponding to an economically active population, married or in a stable union and with low schooling, a factor that can directly interfere with therapeutic adherence and self-care practice<sup>8-9,17</sup>.

The physical limitations caused by leprosy often prevent people from seeking work conditions that require significant effort, precise, delicate movements, and the need to develop repetitive skills. As a result, these restrictions have led more and more people to seek welfare benefits as a survival strategy in low-income family contexts<sup>9</sup>.

As for the clinical form of leprosy treated, the multibacillary operational classification predominated, with up to 5 years of discharge due to cure and some type of leprosy reaction up to the time of the survey. The majority had some degree of physical disability and evidence of nerve involvement, corroborating data from previous studies carried out in Brazil<sup>8-17</sup>.

However, national and international studies warn of the relevance and contribution of self-care groups in terms of knowledge about the disease and its possible consequences. Preventing the onset or worsening of disabilities provides better management of comprehensive care, reduces health costs, favors social interaction in the fight against stigma, allowing for timely inclusion in rehabilitation programs when necessary<sup>18-19</sup>.

Studies carried out in hyperendemic countries, such as Brazil and India, have analyzed WHOQOL-bref domain scores and found that the physical domain was the most affected, followed by the environmental and psychological domains<sup>20-22</sup>. These conditions, combined with the individual's low self-perception, compromise aspects of quality of life and, consequently, the performance of basic and more complex activities. In Brazil, there is still no specific and valid instrument for leprosy that assesses the health-related quality of life of these people, so there is a need for a tool capable of encompassing the peculiarities of the impact on this population.

Therefore, the sociodemographic variables that showed the greatest significance when associated with impaired WHOQOL-bref, especially aspects of the physical domain, show that individuals in situations of social vulnerability, with low levels of schooling, and in a state of poverty are more likely to develop physical disabilities in the context of leprosy due to low adherence and participation in health promotion educational actions<sup>23-24</sup>.

Regarding functionality related to activities of daily living, most of the participants had some kind of limitation, corroborating a study that associates these limitations with the presence of disability and/or deformity because of the pathophysiological process of leprosy<sup>25</sup>.

By associating the SALSA scale scores with sociodemographic and clinical variables, it was possible to see: the statistical significance of mild to moderate functional limitation among men of working age, with low family income, who do not practice physical activity, who are affected by leprosy neuritis, and with some degree of physical disability. A recent study carried out in northeastern Brazil found similar indicators for this population, who, as part of a family in a situation of financial and social vulnerability, may have their productivity and income directly affected, leading them to depend on government aid<sup>9</sup>. The presence of some degree of physical disability consequently prevents them from practicing regular physical activity, which could lead to healthy lifestyle habits.

Contrary to a previous study, the high level of self-esteem among the participants, contrary to a previous study<sup>7</sup>, may have been influenced by some aspects, including the use of a generic instrument, which may have limited the results and not been sufficient to



reveal the particularities of these circumstances. When analyzing the association between self-esteem and sociodemographic and clinical data, there was greater significance for high self-esteem in men who did not consume alcohol and/or cigarettes, had a low family income, and suffered from neuritis. Considering this context, a study links results with positive outcomes to the relevance of knowledge and practice of self-care as a fundamental role in minimizing health risks, improving levels of self-esteem, and combating social stigma in this clientele<sup>8,26</sup>.

Regarding the comparison between health-related quality of life and functionality, it was found that participants without any limitation in functionality had a better perception of WHOQOL-bref, especially in the physical, psychological, and environmental domains. According to this finding, the main aspects highlighted in the scientific literature are the importance of public policies aimed at leprosy; easy access to health services; effective care practices aimed at diagnosis/ treatment; and encouraging self-care, with significant social actions to prevent physical and functional disabilities, which can raise awareness and involve family members and the entire community<sup>25, 27-28</sup>. Considering the role of nursing care in this context, from primary care to the referral service, longitudinal care encompasses interventions that include facilitating access to health services, promoting health education actions with a focus on infection prevention, treatment management, cures, and possible implications as a result of this public health problem.

Furthermore, when comparing WHOQOL-bref and levels of self-esteem, it was possible to see a positive reciprocal relationship, that is, people with high self-esteem had a better perception of quality of life in all the domains investigated. Consistent with this outcome, the study values the importance of this harmony and highlights the importance of the therapeutic bond established between professionals and patients through self-care groups, considered a tool for coping with the disease and providing physical and psychosocial improvement for participants<sup>24</sup>.

The limitations of this study include the selection of participants for convenience due to the impact of the health restrictions imposed by COVID-19, since the sample achieved during the data collection period may not reflect the broad reality of the population in question. The lack of specific validated instruments to investigate the impact of WHOQOL-bref on the self-esteem of the population studied may have influenced the results. Further studies are therefore recommended to improve an accurate assessment, considering the particularities of people affected by leprosy and its diseases.

## CONCLUSION

The data presented in this study shows compromised health-related quality of life and limited functionality in the activities of daily living of people post-discharge from leprosy treatment. However, there was high self-esteem among the participants even in the face of adverse conditions related to the sequelae of treatment. When the WHOQOL-bref, functionality, and self-esteem domains were compared, the study found that people without any functional limitations had a better perception of quality of life, especially in the physical, psychological, and environmental domains. Those with high self-esteem showed better WHOQOL-bref in all the domains investigated.

Considering the above, some aspects of leprosy are compromised and limited during the post-discharge period of multidrug therapy, especially regarding physical and functional issues. Longitudinal care and interdisciplinary teamwork are therefore essential during this therapeutic phase. It is up to nurses to play an active role in monitoring this population in the face of the chronic condition caused by the clinical and social vulnerability of the disease. It is recommended that the professionals involved be trained to draw up and implement a line of care for this clientele, organizing care measures to reintegrate these people into the community to combat stigma through educational actions, damage prevention, disabilities, and deformities.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Fortunato CN, Freire MEM**. Drafting the work or revising it critically for important intellectual content - **Fortunato CN, Nogueira J de A, Brito KKG de, Silva AC de O, Bezerra VP, Mendes M da S, Freire MEM**. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Fortunato CN, Nogueira J de A, Brito KKG de, Silva AC de O, Bezerra VP, Mendes M da S, Freire MEM**. All authors approved the final version of the text.

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