

## Evaluation of the physical limitations, psychosocial aspects and quality of life of people affected by leprosy<sup>1</sup>

Avaliação das limitações físicas, aspectos psicossociais e qualidade de vida de pessoas atingidas pela hanseníase

Evaluación de las limitaciones físicas, aspectos psicosociales y calidad de vida de personas atendidas por la hanseniasis

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### ABSTRACT

**Objective:** Analyze the aspects related to the physical, psychosocial and quality of life of people affected by leprosy. **Method:** Quantitative, cross-sectional study. The Screening Activity Limitation and Safety Awareness (SALSA), Social Participation and e World Health Organization Quality of Life (WHOQOL-bref) scales were applied with 31 subjects. **Result:** The majority of the participants presented some degree of physical and social restriction. The correlation with the degree of disability highlighted that the patients who presented restrictions also had degree of disability II. About the quality of life, the psychological domain and the social relations showed the highest averages, while the physical and the environmental had the lowest ones. **Conclusion:** It is necessary to prioritize and intensify actions to prevent disability in leprosy.

Descriptors: Leprosy, Self-care, Quality of life.

### RESUMO

**Objetivo:** Avaliar os aspectos referentes as limitações físicas, psicossociais e qualidade de vida das pessoas atingidas pela hanseníase. **Método:** Estudo quantitativo, transversal. Foram aplicadas as escalas *Screening Activity Limitation and Safety Awareness* (SALSA), Participação

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Social e *World Health Organization Quality of Life* (WHOQOL-bref) com 31 sujeitos. **Resultado:** Evidenciou-se que a maioria dos participantes apresentava algum grau de restrição física e social. Correlacionando com o grau de incapacidade, destaca-se que os pacientes que apresentaram restrições também possuíam grau II de incapacidade. Quanto à qualidade de vida, o domínio psicológico e o de relações sociais apresentaram as médias mais altas, enquanto o físico e o ambiental tiveram as mais baixas. **Conclusão:** Afirma-se a necessidade de priorização e intensificação das ações de prevenção de incapacidades da hanseníase.

**Descritores:** Hanseníase, Autocuidado, Qualidade de vida.

## RESUMEN

**Objetivo:** Evaluar los aspectos referentes a las limitaciones físicas, psicosociales y calidad de vida de las personas afectadas por la lepra. **Método:** Estudio cuantitativo, transversal. Se aplicaron las escalas Screening Activity Limitation and Safety Awareness (SALSA), Participación Social y World Health Organization Quality of Life (WHOQOL-bref) con 31 sujetos. **Resultado:** Se evidenció que la mayoría de los participantes presentaba algún grado de restricción física y social. Correlacionando con el grado de incapacidad, se destaca que los pacientes que presentaron restricciones, también poseían grado II de incapacidad. En cuanto a la calidad de vida, el dominio psicológico y el de relaciones sociales presentaron las medias más altas, mientras que el físico y el ambiental tuvieron las más bajas. **Conclusión:** Se afirma la necesidad de priorización e intensificación de las acciones de prevención de incapacidades de la lepra.

**Descriptor:** Hanseniasis, Autocuidado, Calidad de vida.

## INTRODUCTION

Hansen's disease (leprosy) is an infectious disease caused by *Mycobacterium leprae* that presents a chronic evolution and affects predominantly the skin and peripheral nerves. In Brazil, it still represents a serious public health problem, since it is a disease inherent in diseases of socioeconomic and cultural origin. It is also marked by the problematic generated by deformities and physical disabilities, which affect not only the physical scope of their patients, but it is one of the causes of stigma and isolation of the person in society, bringing psychosocial problems.<sup>1,2</sup>

Although it is one of the oldest diseases of mankind in the 21<sup>st</sup> century, the detection of new cases remains high in the world, with around 250,000 new cases registered each year. Brazil, in 2015, presented a general disease detection rate of 14.06 new cases/100 thousand inhabitants, corresponding to 28,758 new cases. During the same year, the *Pernambuco* State registered 2,395 new cases and presented a disease prevalence coefficient of 1.88/10 thousand inhabitants.<sup>3,4</sup>

Due to the neurological impairment, it is fundamental to investigate the alterations in the peripheral nerves, because if not diagnosed early, deformities and incapacities may appear. Thus, the neurological evaluation of the eyes, hands, and feet should be performed, and the degree of incapacity of the disease, ranging from 0 (zero) to II (two), should be classified. Level 0 is determined by neural impairment; the level I corresponds to the decrease or loss of sensitivity and the level II indicates the presence of incapacities and deformities of the lagofalmo type, claws, bone reabsorption, fallen hands and feet, ankle contracture, among others.<sup>5</sup>

Given the aforesaid, the physical limitations and daily life activity can lead to a decrease in the quality of life of people affected by this disease. In addition to these restrictions, we can observe the great impact on interpersonal relationships, interfering with family dynamics, socializing with friends, working and interacting with the community.<sup>6</sup>

Therefore, it is highlighted that the development and installation of physical, emotional and social disabilities and disabilities in the individual affected by leprosy is one of the critical points involved with the morbidity and chronicity of the disease, and that it should be prioritized in disease control actions, in the practices of care and follow-up of the cases.

The population's lack of knowledge about the disease is the main cause of fear and prejudice and even though it already has a cure, it still faces several difficulties for its control. Examples of such issues are late diagnosis, inadequate treatment, difficulties in accessing comprehensive care, and large numbers of people with sequelae.

Hence, considering the context of illness that can lead to physical deformities, discrimination and social exclusion, the purpose of this study was to analyze the biopsychosocial aspects regarding the limitations experienced and the quality of life of the leprosy-affected people.

## METHODS

It is a cross-sectional study with a quantitative approach, which was carried out in *Recife* city, *Pernambuco* (PE) State, over the period from September 2015 to April 2016. Two health services were selected; one was a polyclinic and an ambulatory for health dermatology from a State hospital. These were chosen because they are a reference for the treatment of leprosy and have self-care groups where topics about disability prevention (physical and psychosocial) are discussed.

Patients older than 18 years old were invited to participate in the study; in post-discharge treatment or follow-up and participants in self-care groups. This resulted in a convenience sample that totaled 31 subjects. Data were collected by consulting patients' records (identification, operational classification of leprosy and degree of incapacity) and internationally validated questionnaires related to activity limitation - SALSA Scale (Screening Activity Limitation and Safety Awareness); restriction of social participation - Scale of Social Participation; quality of life (World Health Organization Quality of Life, WHOQOL-BREF).

The SALSA scale is used to measure activity limitation through the patient's self-perception of what he or she can perform in daily life activities. The score ranges from 0 to 80 and higher scores are indicative of increasing limitations in performing activities. The degrees of limitation are classified as follows: without limitation (up to 24), slight limitation (25 to 39), moderate limitation (40 to 49), severe limitation (50 to 59) and extreme limitation (60 to 80).<sup>7</sup>

The scale of Social Participation uses the concept of "pair" and aims to scale the restriction to social participation.<sup>8</sup> The scale covers eight of the nine domains of the activity and participation component of the International Classification of Functioning (ICF), composed of 18 items, and its score

ranges from 0 to 90. The degree of restriction are classified as follows: no restriction (0 to 12), slight restriction (13 to 22), moderate restriction (23 to 32), severe restriction (33 to 52) and extreme restriction (53 to 90).<sup>9,10</sup>

The Quality of Life Scale (WHOQOL-BREF) consists of 26 questions. The first two questions are about the general quality of life and the other 24 are about the domains: physical, psychological health, social relationships and the environment.<sup>11</sup>

The collected data were organized into spreadsheets and tabulated in Microsoft Excel 2013 software. They were then transformed into tables and graphs, and also discussed in the light of the reference literature on leprosy, physical and psychosocial limitations and quality of life.

This study composes the research project “Self-Care practices of leprosy-affected people: singularities and challenges”, approved by the Research Ethics Committee from the *Universidade de Pernambuco* and approved under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 24821313.4.0000.5192. The subjects of the study had access to the Free and Informed Consent Term, which they signed, then expressing their desire to participate in the research, in compliance with ethical principles and according to the Resolutions No. 466/2012 and No. 510/2016 from the National Health Council.

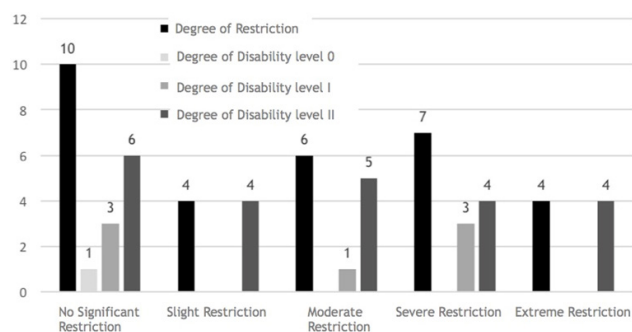
## RESULTS

Thirty-one patients within the age group from 32 to 76 years old have participated of this study. Males accounted for 61% of the sample and 39% for females. The majority of the individuals presented the multibacillary operational classification, with the percentage of 87.1% paucibacillary obtained the percentage of 9.7% and 3.2% of the sample did not present a classification recorded in the medical records. Regarding the degree of incapacity of the interviewees, 3.2% showed level 0; 22.6% level I, and 74.2% level II.

The Social Participation Scale applied with the subjects of the study, addresses questions about the involvement and relationship of individuals with family, friends and community, as well as questions about self-perception. During his application he is asked, for example, if the individual receives the same respect in the community as his partner, if he works as much as his partner and if his opinion is important in the family discussions.

Herein, it was possible to show that most of the patients, 68% (n=21) of the sample, had some degree of restriction (slight, moderate, severe or extreme), as indicated in **Figure 1**. It is also worth noting that when comparing the degree of disability of patients with the degree of restriction of Social Participation, it was possible to verify that all the patients with some level of restriction had degree of incapacity either level I or II.

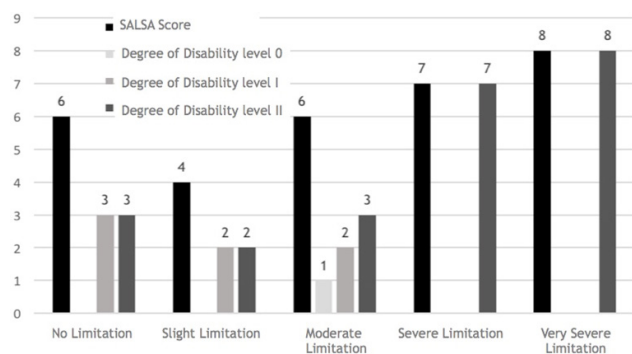
**Figure 1 - Degree of social restriction related to the degree of disability in leprosy-affected patients, Recife-PE, 2016.**



With regards to the physical limitation, which is assessed by the SALSA scale, the lower the score, the less difficulty in performing daily life activities the patient will have; while higher scores indicate increasing levels of activity limitation. In this study, it was identified that most subjects present very severe (26%) or severe (23%) limitation to perform their daily life activities, as highlighted in **Figure 2**.

Correlating the classification of physical limitation of SALSA with the Degree of Disability, it was observed that all patients with very severe and severe limitation presented degree of disability level II.

**Figure 2 - SALSA scale limitation score related to the degree of disability in leprosy-affected patients, Recife-PE, 2016.**



In the analysis of the quality of life, performed through the WHOQOL-BREF scale, the higher the average values of the domains, the higher the quality of life and the values are presented in percentage. Thus, it was identified that the psychological domain and the social domain represent the domains with the highest averages. There is an expressive contrast between the minimum and maximum in the social domain, then pointing out difficulties in the personal relationships of some subjects interviewed, as presented in **Table 1**.

**Table 1** - Measurements of centrality and dispersion from the WHOQOL-BREF quality of life scores of leprosy patients, Recife-PE, 2016.

WHOQOL-BREF Domain	Minimum	Maximum	Median	Average	± Standard Deviation
Physical	7	82	50	47	± 19.86
Psychological	21	92	67	63	± 18.86
Social Relationships	8	100	67	62	± 28.06
Environmental	19	75	50	47	± 14.22
Overall Life Quality	23	83	59	55	± 16.95

The averages of the physical and environmental domain were the lowest and presented the same percentage, which contributed to the decrease in the general quality of life score of the interviewees, which resulted in 55%. The physical domain had the lowest minimum score among all domains, which can be attributed to the incapacitating power of the disease since most of the subjects in the study have installed capacity.

The results found and analyzed together with the degree of incapacity make it possible to obtain a broader and more reliable view of the living conditions of these patients, since the majority of those who participated in this study had degree of disability level II, and among these, many had significant degrees of restriction and limitation.

## DISCUSSION

The study identified significant levels of activity limitation, restriction of social participation, and a low percentage of quality of life of the interviewed people affected by leprosy.

Regarding the characterization of the participants, a study by Oliveira *et al.*<sup>12</sup> shows that there is a greater probability that males are affected by leprosy, this finding corroborates the results presented. Considering the operational classification, most of the sample is classified in the multibacillary category and there is a large percentage of individuals that also present some degree of physical disability,<sup>13</sup> as found in the present study.

The analysis of social participation revealed that the highest percentage of patients was classified with some degree of restriction of social participation. Thus, according to Santos,<sup>6</sup> these patients need a more qualified and integral health care. Despite this finding and the history of exclusion and prejudice that leprosy has, it is not possible to relate only the disease to the restriction to social participation. It is fundamental to analyze other variables that may interfere.

When correlating the degree of restriction obtained in the scale of Social Participation with the degree of physical disability, of the 21 participants, 17 had level II disabilities and the remaining level I. A similar result was found by Santos,<sup>6</sup> who in his study reveals that individuals who presented some degree of social restriction (slight, moderate, severe or extreme), had, in the majority, degree of disability level I.

In this study, unlike what was found by Monteiro *et al.*<sup>3</sup> and Santos *et al.*,<sup>14</sup> in which the majority of the participants

had scores of slight limitations, it was found that most had severely limited scores. This may suggest that there were problems in the care path of the patients as a late diagnosis of the disease and consequently the installation of degrees of physical incapacity, or difficulties in access to services that promote the prevention of disabilities and rehabilitation.

When performing a comparative analysis between the results of activity limitation and the degree of disability, Santos<sup>6</sup> found that there was no significant association between the scores. In contrast, in the present study, it was identified that the higher the degree of physical disability, the higher the activity limitation score. The finding is related to the profile of the participants in the self-care groups, who mostly have people with disabilities already existing.

The data analyzed indicate a poor life quality. This finding disagrees with those of Sena,<sup>11</sup> who states in another study that quality of life is positive in most aspects measured. If the general quality of life of the participants is observed, the average is slightly above the 50 points, diverging from the average of more than 60 points of the Sena analysis.<sup>11</sup>

Herein, as in the research by Simões *et al.*,<sup>15</sup> the psychological domain and the social relationships domain were the ones that obtained the highest averages. It is emphasized that the psychological domain is composed of questions that involve positive and negative feelings, self-esteem, body image and appearance, spirituality and personal beliefs. Already the domain of social relationships has questions about personal relationships, social support (help) and sexual activity.

The physical domain, which involves questions about pain and discomfort, mobility and activities of everyday life and the environment domain, which covers questions about physical security and protection, home environment and financial resources, were the ones that reached the lowest averages. These two domains contribute to the worsening of the quality of life of the studied population. It is observed that in the analysis of Sena<sup>11</sup> and Simões *et al.*<sup>15</sup> the same data related to these two domains is found.

The classifications resulting from the application of the scales allowed obtaining a situational diagnosis of the biopsychosocial aspects of the study participants. There is a greater percentage of people who have some restriction, with very severe limitation and presents a low quality of life. This knowledge of the limitations and restrictions caused by the disease enables an analysis that contributes to the strengthening of disability prevention actions and measures that improve the quality of care and of the care offered to leprosy-affected people.

## CONCLUSIONS

The situational analysis performed by this study pointed out how the quality of life of the patients can be affected by the disease. The impact of this and the consequent installation of the disabilities and deformities affects not only the physical scope of the patients, with evident limitations for performing activities of daily living, but also encompasses psychosocial problems, such as social restriction. It was identified that the associations between the levels of commitment indicated by

the scales can subsidize health professionals in understanding the underlying impacts of treating people affected by leprosy.

Given the aforementioned, it is confirmed the need to both prioritize and intensify actions aiming to prevent leprosy-derived disability and also rehabilitate people suffering from this, with the concern that we must have a specialized team capable of attending patients, and always seeking comprehensive care as well.

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