

Profile of functionality of persons affected by leprosy*

Perfil de funcionalidade de pessoas afetadas pela hanseníase


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ABSTRACT

Objective: to analyze the functioning and disability profile of persons affected by leprosy. **Methods:** a quantitative study, carried out with 43 people in six reference units with support groups for self-care in leprosy. A sociodemographic and clinical questionnaire and the World Health Organization Disability Assessment Schedule instrument were used. The analyses used descriptive statistics, the chi-square test of adjustment adequacy for categorical variables, binomial and Mann-Whitney. **Results:** the median (interquartile range) in the Participation, Mobility, Cognition and Life Activities domains were 37.5 (20.8-54.2), 25.0 (6.3-56.3), 20.0 (0.0-40.0) and 10.0 (0.0-40.0), respectively, representing the impact of the disease in these domains. **Conclusion:** the functionality scores were higher in the Participation and Mobility domains, reflecting physical disabilities, discrimination and stigma in the lives of people affected by leprosy. **Descriptors:** Leprosy; Self Care; International Classification of Functioning, Disability and Health; Disabled Persons; Disability Evaluation.

RESUMO

Objetivo: analisar o perfil de funcionalidade e deficiência de pessoas afetadas pela hanseníase. **Métodos:** estudo quantitativo, realizado com 43 pessoas em seis unidades de referência, contendo grupos de apoio ao autocuidado em hanseníase. Foram utilizados um questionário sociodemográfico e clínico e o instrumento *World Health Organization Disability Assessment Schedule*. As análises utilizaram estatística descritiva, os testes de qui-quadrado de adequação de ajustamento para as variáveis categóricas, binomial e Mann-Whitney. **Resultados:** a mediana (intervalo interquartil) nos domínios Participação, Mobilidade, Cognição e Atividades de Vida foram, respectivamente, 37,5 (20,8-54,2), 25,0 (6,3-56,3), 20,0 (0,0-40,0) e 10,0 (0,0-40,0), representando o impacto da doença nesses domínios. **Conclusão:** as pontuações de funcionalidade foram maiores nos domínios Participação e Mobilidade, como reflexo das incapacidades físicas, discriminação e estigma na vida das pessoas afetadas pela hanseníase.

Descritores: Hanseníase; Autocuidado; Classificação Internacional de Funcionalidade, Incapacidade e Saúde; Pessoas com Deficiência; Avaliação da Deficiência.

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Introduction

Leprosy has a chronic character, a long incubation period, delayed diagnosis and nerve involvement, and has great relevance to public health due to its power to develop physical and functional disabilities and deformities, affecting mainly the economically active age group⁽¹⁾. About 28% of the people affected by the disease develop disabilities, and many of them are already diagnosed with grade II disabilities, showing that this diagnosis still occurs late⁽²⁾.

It is noteworthy that functionality, according to the International Classification of Functioning, Disability and Health (ICF), implies the expanded assessment of a person, in several domains, considering the functions and structures of the body, activities, participation, environmental factors and personal factors⁽³⁻⁵⁾. The ICF distinguishes that disabilities can lead to loss of socialization and that this can be due to a social context with vulnerabilities, thus in the context of leprosy discrimination and/or stigma can affect functionality⁽³⁾.

In this context, the World Health Organization developed the World Health Disability Assessment Schedule (WHODAS), based on the ICF, which suggests the measurement of the impact of several health situations regarding functionality. It was created with the objective of analyzing from activity limitations to participation restrictions experienced by people, despite their clinical diagnosis, and addresses six domains of life: Cognition; Mobility; Self-care; Interpersonal Relationships; Life Activities and Social Participation. The instrument grants delineation and a general measurement of functioning and disability that can be used in adult populations from diverse cultures⁽³⁾.

It is thus highlighted that the physical disabilities caused by leprosy can lead to social discrimination and stigma, with serious psychosocial repercussions, which can lead to the formation of barriers to social participation⁽⁶⁾. Studies show a causal relationship between physical disability, restricted social partici-

pation and functional limitation for people affected by the disease after discharge from treatment⁽⁷⁻⁸⁾.

The nurse has an elementary role in structuring the knowledge about the prevention of disabilities, health promotion, self-care guidelines in the context of leprosy. In this sense, knowing the situational diagnosis of functional disability of people in multi-drug therapy, treatment for leprosy reaction or post-discharge enables the search for strategies for care based on the needs of people affected by leprosy.

In view of the above, in which it is pointed out that functionality is the result of the interaction of several contextual factors, this study aimed to analyze the functioning and disability profile of persons affected by leprosy.

Methods

Cross-sectional research conducted between January and July 2018, in the city of Recife and the Metropolitan Region, with participants of six active leprosy self-care support groups, in health units that are reference for the follow-up of people affected by the disease.

The number of members of the self-care groups during data collection was 78 participants. The research was presented at the meetings of the groups where there was an invitation for participation and scheduling of interviews for those who met the inclusion criteria. The sample was designed in a non-probabilistic way (convenience/accessibility) and composed of a total of 43 participants. The inclusion criteria were being a participant in the self-care groups, having been diagnosed with leprosy, under polycythiomatic treatment, treatment for leprosy reaction or post-discharge, aged 18 years or older, and having been under treatment for the disease for at least three months. The exclusion criteria were having physical, sensory and/or motor disability already installed before the diagnosis of leprosy. This criterion was established aiming to visualize the presence of disabilities

and/or deformities resulting from the physiopathological process of the disease and their impact on the functionality and quality of life of these people.

Data collection was performed in a single moment in which two instruments were applied. The first consisted of sociodemographic and economic questions, such as gender, age, ethnicity, marital status, origin, work status, education, housing conditions, monthly income and clinical profile (operational classification; clinical form; leprosy reaction and degree of physical disability). For information about the clinical profile, we used data from the participants' medical records.

The version of WHODAS 2.0 used in this study is the 12+24 interviewer-applied version, totaling 36 questions that address the difficulties experienced by respondents in six life domains during the 30 days prior to the interview. It is composed of answers organized on a five-point Likert-type scale ("no difficulties" to "extreme difficulties/not possible"). The score is made up from the sum of the recoded item scores within each domain and the sum of all six domain scores. Higher values represent greater impairment in the domain analyzed and the score is presented in values ranging from zero to 100 (where zero = no impairment; 100 = complete impairment)^(3,9).

Extensive field tests have been conducted worldwide, demonstrating good reliability and item-response characteristics of this instrument, as well as a well-constructed factor structure that remains responsive to cultural and population differences of individuals⁽³⁾.

The instrument was structurally robust and all items were selected based on item response theory, that is, when data from questionnaires and tests are obtained from the execution of mathematical patterns. In this study, the syntaxes suggested by the World Health Organization guided the calculation of WHODAS 2.0 scores⁽³⁾.

The normality of the continuous numerical variables was verified with the Kolmogorov-Smirnov

test. Since the continuous variables did not have a normal distribution, they were described with the median and the interquartile range, minimum and maximum values. The Mann-Whitney "U" test was used to compare the functional disability scores according to sex, operational classification and leprosy reaction.

The categorical variables were presented as absolute and percentage frequency. A significance level of less than 5% was adopted. The analyses were performed with the software Statistical Package for the Social Sciences for Windows, version 20.

The instruments were applied in person by the researcher in a reserved and calm environment, requiring only one moment to obtain the information. The research was developed after approval by the Ethics Committee for Research with Human Beings of the Hospital Complex of the University of Pernambuco, under Opinion No. 2,816,057/2018.

Results

Forty-three people affected by leprosy, members of self-care support groups, participated in the study. Among them, it was found that 23 (53.5%) participants were male, 46.5% were between 40 and 59 years old, and 53.5% declared themselves as brown. In addition, 53.5% of the sample came from regions other than Recife or the Metropolitan Region.

As for the economic and educational status, 62.8% users had monthly income between one and two minimum wages and 51.0% users had four to seven years of study, respectively. Regarding marital status, there was a predominance of 35.0% single, and regarding work status, the highest percentage was 35.0% retired. In addition, 86.0% of the study participants owned their own homes, 35% had been participating in leprosy self-care support groups in one of the health units for more than a year, followed by more than three months (4.7%) and between three and six months (2.3%).

Regarding the clinical profile of the partici-

pants, 90.2% of them presented the multibacillary operational classification and only 9.8% were classified as paucibacillary. Regarding the clinical form, 50.0% presented the Virchowian form, 47.4% the dimorphic form, and 2.6% the tuberculoid form.

About the disability grade, 15.8% of the participants had grade zero, 36.8% grade I and 47.4% grade II (p=0.052). In addition, 57.9% of the participants answered “yes” about having had leprosy reaction during treatment and/or post-discharge, while 42.1% answered “no”.

Table 1 shows the results distributed in points according to the six domains. The domain with the highest median was Participation (37.5), followed by Mobility (25.0), thus reflecting the impact that the disease has on these domains.

Table 1 – Scores of the domains of functional disability of persons affected by leprosy participating in self-care support groups. Recife, PE, Brazil. (n=43)

Domains	Median (Inter-quartil interval)	Minimum	Maximum
Cognition	20.0 (0.0; 40.0)	0.0	70.0
Mobility	25.0 (6.3; 56.3)	0.0	87.5
Self-care	0.0 (0.0; 40.0)	0.0	80.0
Interpersonal relations	0.0 (0.0; 25.0)	0.0	100.0
Life activities	10.0 (0.0; 40.0)	0.0	80.0
Participation	37.5 (20.8; 54.2)	0.0	87.5

Table 2 shows that no significant differences were identified between the medians of the functional disability scores in the comparisons by sex, operational classification and leprosy reaction.

Table 2 – Median (interquartile range) of functional disability domain scores of persons affected by leprosy participating in self-care support groups according to gender. Recife, PE, Brazil. (n=43)

Domain	Sex		P*	Operational Classification		P	Leprosy reaction		P
	Female (n=20)	Male (n=23)		Multibacillary (n=37)	Paucibacillary (n=4)		No (n=16)	Yes (n=22)	
Cognition	20.0 (0.0; 28.8)	20.0 (5.0; 40.0)	0.700	20.0 (0.0; 35.0)	32.5 (10.0; 62.5)	0.260	17.5 (5.0; 40.0)	24.3 (7.5; 40.0)	0.730
Mobility	25.0 (0.0; 48.4)	25.0 (6.3; 56.3)	0.450	25.0 (3.1; 53.1)	40.6 (10.9; 75.0)	0.390	18.8 (1.6; 70.3)	34.4 (4.7; 56.3)	0.550
Self-care	10.0 (0.0; 40.0)	0.0 (0.0; 40.0)	0.700	0.0 (0.0; 40.0)	15.0 (0.0; 67.5)	0.700	0.0 (0.0; 47.5)	18.6 (0.0; 32.5)	0.950
Interpersonal relations	4.2 (0.0; 25.0)	0.0 (0.0; 25.0)	0.590	0.0 (0.0; 25.0)	4.2 (0.0; 64.6)	0.870	0.0 (0.0; 22.9)	10.6 (0.0; 25.0)	0.710
Life activities	5.0 (0.0; 37.5)	10.0 (0.0; 50.0)	0.570	10.0 (0.0; 40.0)	30.0 (5.0; 62.5)	0.390	5.0 (0.0; 47.5)	25.9 (0.0; 42.5)	0.630
Participation	37.5 (20.8; 51.0)	41.7 (16.7; 54.2)	0.550	37.5 (20.8; 54.2)	41.7 (9.4; 74.0)	0.890	39.6 (25.0; 65.6)	40.9 (19.8; 54.2)	0.990

*Mann-Whitney U-test

Discussion

The limitations of this research may be associated with the sampling process, due to the dynamic behavior of the members of self-care groups and the groups themselves, in addition to the participation of individuals in this space being subject to availability and interest, interfering in the data collection process.

In addition, there is the cross-sectional design, because it is not possible to identify the cause and effect relationship of the problems evidenced in the scores of functional disability domains and the impact of the existence of self-care support groups in the prevention and monitoring of functional limitations of participants.

This study contributed to the situational diagnosis of the functionality of people affected by leprosy. The use of instruments such as WHODAS 2.0 enables the practical and routine incorporation of an ICF-based instrument in the health care of people affected by leprosy⁽¹⁰⁾. This information can aid in understanding the impact of the disease and thus contribute to the discipline and planning of the work process of nurses and other health professionals in assisting affected populations. In addition, it adds results and discussions that further the scientific study of Nursing.

When considering the profile of the population, most participants were male, which is corroborated by some studies⁽¹¹⁻¹²⁾. Also pointed out are factors that can delay diagnosis and increase the likelihood of physical disabilities, such as increased exposure to the bacillus and the fact that males are less likely to use health care services⁽¹³⁾.

Regarding the low levels of education and income, the results of this research are similar to those of other studies that characterized people affected by the disease in Brazil. It is important to highlight that the level of education can contribute to the difficulties in understanding information by people affected by the disease and reflect in problems in the Cognition domain. This context can hinder and negatively interfere in the understanding of the disease, diagnosis, treatment and self-care of the participants and highlight the economic losses at the individual, family and social levels^(12,14).

Regarding age and work status, studies on the epidemiological situation of leprosy have reported that persons affected by the disease are in the economically active age group^(12,15-16). Surveys in Alagoas (23.7%) and Pará (57.6%) corroborate the socioeconomic characterization found in this study⁽¹⁴⁻¹⁵⁾. Furthermore, it has been pointed out in the literature that social inequalities impact on higher disability scores, indicating that poor living standards are common in people living with disease-related disabilities⁽¹⁷⁻¹⁸⁾.

Regarding operational classification and clinical form, the multibacillary operational classification

was the most predominant in the populations of some studies^(1,7,13), similarly to the result found in this study. The same literature mentioned above also discussed the relationship between the large number of diagnoses of multibacillary cases and late diagnoses, since leprosy is a pathology that affects several organs and the multibacillary clinical forms are the most severe and potentially infectious.

Among the infectious-contagious diseases, leprosy is the main cause of permanent physical disability due to nerve involvement, which can lead to deformities, decreased work capacity, limited social life and psychological problems, in addition to its chronic nature and long incubation period^(2,19).

Functional disability involves issues such as adaptation strategies in the participants' daily life activities routine; the presence of an active health professional team that can guide the process of care practices, their own perception of illness and of health-illness, items that were not object of analysis in this study⁽⁷⁾.

It is also noteworthy that the participants were part of a self-care support group where several issues related to the theme were addressed, which may have influenced the construction of self-care practices of these people and this may have contributed to them not identifying difficulties in the aspects analyzed in this domain.

Despite the historical context of discrimination, stigma, isolation and lack of information, in which people affected by the disease tend to be excluded and disabled from social relationships and economic activities⁽⁷⁻⁸⁾, participants did not perceive difficulties in the Interpersonal Relationships domain. Being part of a self-care support group, a space for sharing experiences and difficulties, can influence their perception of friendships and relationships among people with the same challenges⁽¹⁶⁾.

People affected by leprosy may experience restrictions in participating in life situations, even in the absence of disabilities. They may experience changes in social behavior, leading to isolation and low self-

-esteem, and are susceptible to the prejudice and stigma of the disease due to the presence of physical disability and dermatoneurological lesions. It becomes necessary, considering the disabling character and the stigma related to leprosy, to develop an integrated approach to people affected by leprosy regarding the biopsychosocial aspects. Issues such as disability, activity limitation and participation restriction should be considered fundamental and assessed during and, if possible, after treatment⁽⁷⁻⁸⁾.

Conclusion

The study identified that functionality in the Participation and Mobility domains presented the highest scores, reflecting the characteristics of leprosy in the daily lives of those affected by physical disability, discrimination and stigma, regardless of gender, operational classification and leprosy reaction. The data obtained can be used in the follow-up of patients over time, as well as before and after interventions, thus contributing to the improvement of health care for this population.

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Collaborations

D'Azevedo SSP contributed to the conception and design, data analysis and writing of the article. Arruda GA and Barbosa JC contributed to data analysis and interpretation. Alves MGT and Souza NMN contributed to the data collection and analysis and writing of the article. Santos DCM contributed to concep-

tion and design, data analysis, article writing, relevant critical review of the intellectual content, and approval of the final version to be published.

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