

# Activity limitations in leprosy and their association to cognition and neuropsychiatric symptoms

*Limitações de tarefa na hanseníase e sua associação com cognição e sintomas neuropsiquiátricos*  
*Limitaciones de tarea en la enfermedad de Hansen y su relación con cognición y síntomas neuropsiquiátricos*

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## ABSTRACT

**Objectives:** to analyze activity limitations in patients with leprosy and their association to cognition and neuropsychiatric symptoms. **Methods:** this cross-sectional design study included sixty patients with multibacillary leprosy assisted at a reference center. Participants were divided according to their physical disability and submitted to instruments assessing daily activities (basic and instrumental), cognitive functions, and neuropsychiatric symptoms. The order of the instruments was random to avoid any interference of test sequence on the results. **Results:** fifty-five percent of the participants presented physical disabilities. All patients were independent in performing basic activities but sixty-six percent presented difficulties in performing instrumental activities. Cognitive decline and neuropsychiatric symptoms were seen in advanced stages of the disease, but they were more associated to patient age than to leprosy. **Conclusions:** leprosy patients presented physical disabilities and difficulties in performing instrumental daily activities. Cognitive decline and neuropsychiatric symptoms were more associated to aging than to leprosy itself.

**Descriptors:** Leprosy; Activities of Daily Living; Physical Functional Performance; Cognition; Neuropsychological Tests.

## RESUMO

**Objetivos:** analisar as limitações de tarefa em pacientes com hanseníase e sua associação com cognição e sintomas neuropsiquiátricos. **Métodos:** este estudo transversal incluiu 60 pacientes com hanseníase multibacilar atendidos em um centro de referência. Os participantes foram divididos segundo a disfunção física e avaliados quanto às atividades diárias (básicas e instrumentais), às funções cognitivas e aos sintomas neuropsiquiátricos. A ordem de aplicação dos instrumentos foi aleatória para evitar interferência da sequência dos testes sobre os resultados. **Resultados:** dos participantes, 55% apresentaram disfunção física. Todos os pacientes eram independentes nas atividades básicas, mas 66% mostraram dificuldades nas atividades instrumentais. Declínio cognitivo e sintomas neuropsiquiátricos foram observados em estágios avançados da doença, porém estes estavam mais associados à idade do paciente do que à hanseníase. **Conclusões:** pacientes com hanseníase evidenciaram disfunção física e dificuldades nas atividades diárias instrumentais. Declínio cognitivo e sintomas neuropsiquiátricos estão mais associados ao envelhecimento do que à hanseníase. **Descritores:** Hanseníase; Atividades Cotidianas; Desempenho Físico Funcional; Cognição; Testes Neuropsicológicos.

## RESUMEN

**Objetivos:** analizar limitaciones de tarea en pacientes con Lepra y su relación con cognición y síntomas neuropsiquiátricos. **Métodos:** este estudio transversal incluyó 60 pacientes con Lepra multibacilar atendidos en centro de referencia. Participantes fueron divididos segundo la disfunción física y evaluados cuanto a las actividades diarias (básicas e instrumentales), funciones cognitivas y síntomas neuropsiquiátricos. Orden de aplicación de los instrumentos aleatoria para evitar interferencia de la secuencia de tests sobre los resultados. **Resultados:** de los participantes, 55% presentaron disfunción física. Todos pacientes eran independientes en las actividades básicas, pero 66% mostraron dificultades en las actividades instrumentales. Declive cognitivo y síntomas neuropsiquiátricos fueron observados en etapas avanzadas de la enfermedad, pero estos estaban más relacionados a la edad del paciente que a la Lepra. **Conclusiones:** pacientes con Lepra evidenciaron disfunción física y dificultades en las actividades instrumentales. Declive cognitivo y síntomas neuropsiquiátricos están más relacionados al envejecimiento que a la Lepra.

**Descriptorios:** Enfermedad de Hansen; Actividades Cotidianas; Desempeño Físico Funcional; Cognición; Pruebas Neuropsicológicas.

## INTRODUCTION

Leprosy is an endemic and disabling condition which is stigmatized and generally connected to situations of poverty and to fragile health systems. It is an infectious disease that affects the person's skin and damages peripheral nerves<sup>(1-2)</sup>.

In Brazil, the number of new cases of leprosy has been decreasing over the years. The country, however, is still in the sad position of being one of the nations where the disease is most prevalent<sup>(3)</sup>.

Patients with leprosy suffer several biological and psychosocial consequences<sup>(4-6)</sup>. In spite of the disease been characterized by skin problems and sensorimotor disorders, studies point to a larger range of involvement<sup>(7-9)</sup>. Recent publications showed that patients with leprosy have limitations in performing activities of daily living (ADL), and a great susceptibility to physical disabilities and morbidities<sup>(10-12)</sup>. Cognitive decline, as well, was seen in some patients<sup>(13)</sup>. Suicide rates are high among people with leprosy, impacted mainly by motor dysfunctions, social reclusion, and society's prejudice<sup>(14-15)</sup>.

Knowing that physical dysfunction is common in leprosy, the authors conducted this study seeking to assess the functional independence of patients in basic and instrumental ADL, and to investigate if physical disabilities in leprosy impact others systems of the organism, such as the cognitive and the neuropsychiatric. The authors believe that this study should be of interest of the readers of the *Revista Brasileira de Enfermagem*, as it increases the discussion in the field of care in leprosy.

## OBJECTIVES

To analyze activity limitations in patients with multibacillary leprosy and their association to cognition and neuropsychiatric symptoms

## METHODS

### Ethical aspects

This research was conducted in accordance to the Declaration of Helsinki and its protocol was approved by the Ethics Committee of the Federal University of Mato Grosso do Sul. All participants provided written consent prior to the assessments.

### Design, location and period

This is a cross-sectional design study derived from a masters' thesis of the Graduate Program in Health and Development of the Midwest Region of Brazil. The methodological procedures were reported according to STROBE – Strengthening the Reporting of Observational Studies in Epidemiology. Participants were recruited in 2018-2019 at Hospital Sao Juliao – an institution located in the city of Campo Grande/MS/Brazil considered a reference in treating leprosy in Latin America.

### Sample studied

The sample size calculation involved the delimitation of the alfa error in 5%, the statistical power in 80% (1-beta), and the effect

size in 0.45. The effect size was previously stipulated by researchers on what they hypothesized to find about the impairments of participants with regard to ADL. Due to that, sixty patients diagnosed with multibacillary leprosy were enrolled in this study.

Inclusion criteria involved people of both sexes, aged 18 years or more, and diagnosed with multibacillary leprosy. Participants unable to understand the tests, cases of mental confusion and people showing impossibility of attendance to the evaluation center were excluded.

Participants were divided in three groups, according to physical disability: group with no disability, group with mild disability, and group with severe disability. All participants underwent a dermato-neurological evaluation that indicated the diagnosis of multibacillary leprosy. Confirmation of patients' diagnosis was done by tissue analyses (biopsy) at the reference center.

## Methodological procedures

After recruitment, participants were submitted to instruments assessing physical incapacity, ADL, cognitive functions, and neuropsychiatric symptoms. Assessments in each patient were performed on the same day. The order of the application of the instruments was random to avoid any interference of the test sequence on the results.

The evaluation of participants' physical disability occurred by means of the simplified neurological assessment proposed by the World Health Organization, which involves motor and sensorial functions<sup>(16)</sup>. Motor functions were analyzed through the participants' strength on eye muscles, hands, and feet. Sensorial functions were analyzed through the integrity of the patients' vision and through esthesiometry tests. In this instrument, physical disability is classified as 0 when the subject did not show any sensorimotor disability, 1 when some sensorimotor deficit was found (identified by the purple monofilament of the esthesiometer or by a muscle strength of up 4.0), and 2 when the disease is in a more advanced stage (identified by the presence of contractures, deformities, ulcers and other trophic injuries).

The ADL were verified with the Katz Index (KI)<sup>(17)</sup> and with the Screening of Activity Limitation and Safety Awareness (SALSA)<sup>(18)</sup>. The KI assesses its subject's independence in basic ADL such as bathing, clothing, hygiene, transfers, sphincter control, and during feeding. The scale ranges from 0 to 6, with higher scores indicating greater independence on performing these activities. The SALSA, differently, assess subject's independence on instrumental ADL, such as cooking, serving hot liquids, opening/closing bottles, manipulating objects, and other tasks that demand executive processing. For SALSA, values of up to 25 indicate no difficulties in performing the task, values from 25 to 39 indicate mild difficulty, values from 40 to 49 show moderate difficulty in executing the tasks and values above 50 indicate the participant has a severe difficulty in performing the task.

Cognitive functions were assessed with the Frontal Assessment Battery (FAB)<sup>(19)</sup>. This instrument was used to assess the following executive processes: conceptualization, lexical flexibility, motor programming, conflicting instructions, inhibitory control, and environmental autonomy. The scale ranges from 0 to 18, and the higher the scores, the better the cognitive performance.

Neuropsychiatric symptoms were traced through the Self-Reporting Questionnaire (SRQ-20)<sup>(20)</sup>. The instrument score varies from 0 to 20 and higher values indicate the presence of neuropsychiatric symptoms. Researchers elaborated a sociodemographic form to characterize participants according to age, sex, presence of pain and medications in use.

### Data analysis

Data analysis involved descriptive and inferential statistics. Since the Shapiro-Wilk test showed the non-parametric pattern of the data, results were described in number of events, percentage, median and interquartile range.

For the inferential statistic, the chi-square, Kruskal-Wallis and Mann-Whitney U tests were used to compare groups in relation to the outcomes. Spearman's correlation index was applied to verify associations between age, diagnosis time, ADL, pain, neuropsychiatric symptoms, and cognition. Significance was set at 5% ( $p < 0.05$ ).

### RESULTS

This survey involved 63 participants. Three individuals were excluded due to the selection criteria. Exclusions resulted from the absence of diagnostic confirmation ( $n=2$ ) and to one subject who did not want to participate in the research ( $n=1$ ). The final sample size was formed by 60 participants, 31 men and 29 women, with a mean age of  $54.0 \pm 23.5$  years. Fifty-five percent of the patients presented physical disabilities (mild or severe), and the mean diagnosis time of the subjects was of  $4.5 \pm 8.0$  years. Table 1 details participants' sociodemographic and clinical aspects.

Regarding activity limitations, no participant presented a score below 5.0 on KI – indicating good independence of the subjects in performing basic ADL ( $p=0.709$  on between groups comparison). For the SALSAs, there were participants showing none, mild, moderate and severe difficulties in performing instrumental ADL. Table 2 details participants' difficulties in performing the instrumental ADL in each group.

Table 3 shows correlation analyses between age, diagnosis time, pain, ADL, neuropsychiatric symptoms and cognition. With respect to medication, all participants were in use of the drug cocktail proposed by the World Health Organization and by the Brazilian Ministry of Health, namely, rifampicin, dapsone, and clofazimine.

**Table 1** – Socioeconomic and clinical aspects of patients with leprosy assisted in a reference hospital, Campo Grande, Mato Grosso do Sul, Brazil, 2019

Variables	Physical disability (grade)			p
	No disability (0)	Mild disability (1)	Severe disability (2)	
Sample size, n	27	23	10	0.019
Age, years	48.0 (25.0)	57.5 (29.2)	60.0 (23.2)	0.252
Sex, Male – Female, %	44.4 – 55.6	52.2 – 47.8	70.0 – 30.0	0.384
Diagnosis time, years	3.0 (5.5)	5.0 (6.7)	7.0 (17.7)	0.757
Ulcers, %	11.1	4.3	40.0	0.019
Pain, score	0.0 (5.0)	5.0 (9.5)	1.5 (6.2)	0.389
Frontal Assessment Battery, score	15.0 (5.0)	13.5 (6.0)	10.5 (8.2)	0.413
Neuropsychiatric symptoms, score	7.5 (10.0)	11.0 (7.5)	2.5 (7.7)	0.029

Note: Data are arranged in raw numbers for sample size and in percentage for sex and ulcers. The other variables are expressed in medians (interquartile range). The p-value of chi-square test was used for sample size, sex and ulcers, and the p-value of the Kruskal-Wallis test for the other variables.

**Table 2** – Performance of participants on instrumental activities of daily living, Campo Grande, Mato Grosso do Sul, Brazil, 2019

Groups	Difficulties in performing SALSAs				p
	None	Mild	Moderate	Severe	
Physical disability (grade)					
No disability (0), %	48.2	37.0	7.4	7.4	0.102
Mild disability (1), %	17.4	52.2	30.4	0.0	
Severe disability (2), %	30.0	40.0	30.0	0.0	

Note: Data are expressed in percentage. p value of the Chi-square test.

**Table 3** – Correlation analyses involving clinical variables of patients with multibacillary leprosy, Campo Grande, Mato Grosso do Sul, Brazil, 2019

	Age	Diagnosis time	Pain	Katz Index	SALSAs	Cognition	Neuropsychiatric symptoms
Age	1.000	0.324	0.084	-0.005	0.090	-0.339	0.385
Diagnosis time		1.000	-0.071	0.063	0.298	-0.080	0.058
Pain			1.000	-0.208	0.419	-0.246	0.178
Katz Index				1.000	-0.017	0.255	-0.043
SALSAs					1.000	-0.245	0.335
Cognition						1.000	0.340
Neuropsychiatric symptoms							1.000

Note: SALSAs – Screening of Activity Limitation and Safety Awareness. R values of the Spearman correlation tests. Significant values ( $p < 0.05$ ) are highlighted in bold.

### DISCUSSION

Leprosy is a disabling condition that affects the whole family and stigmatizes the patient<sup>(21-23)</sup>. One way to minimize prejudice is to openly discuss leprosy in society<sup>(24)</sup>. Another way is to prepare health care professionals to approach the disease in a comprehensive way so that the patient does not become physically disabled and absent from the social environment<sup>(25)</sup>.

In this scenario, the authors analyzed activity limitations in patients with multibacillary leprosy and investigated if physical disability affects others systems of the organism. Results showed that most participants present physical disability (mild or severe). All patients were independent in performing basic ADL but a good part (66.7% of the sample) presented difficulties in performing instrumental ADL. Difficulties in performing instrumental ADL were associated to diagnosis times. Cognitive decline and neuropsychiatric symptoms – although present – were more associated to aging than to leprosy. The understanding of factors impacting the health of patients with

leprosy is important to provide the best support for families and treatment for patients.

The first thing to be noticed is that groups were homogeneous for age, sex, time since diagnosis, reported pain and functional activities. These results minimize the impact of sociodemographic and clinical profiles on the outcomes. In spite of not having differences for age and time of diagnosis, patients with greater disability tended to be of more advanced age and have a greater time of diagnosis. This aspect is important, and it shows the concomitant impact of disease severity and age on the health of individuals.

In this study, the number of patients with severe disabilities was significantly lower than the number of patients without disabilities and those with mild disabilities. Reasons for that may be related to difficulties of critically ill patients in attending the hospital and to the fact that most patients attended at Sao Juliao hospital are treated before getting into the advanced stage of the disease. New studies should center analyses on patients with advanced physical disabilities to verify whether their clinical and functional profiles are similar to those found here.

Previous authors reported the impact of leprosy on patients' functional independence<sup>(26-28)</sup>. In the present study, groups were homogeneous for basic and instrumental ADL. In spite of this similarity, table 2 showed that 66.7% of patients with multibacillary leprosy presented some difficulty in performing instrumental ADL. This means that physical disability did not interfere on basic ADL, but the data showed a tendency of worsening values on instrumental ADL when physical disability increases. Furthermore, as reported in table 3, there was a significant association between disease severity and instrumental ADL, *illic est*, the greater the affection, the greater the difficulties in performing complex activities. This finding is important because it reinforces that, although physical disability had not been impactful on patients' basic ADL, disease severity showed to interfere on complex ADL.

Skin ulcers represent a serious problem in leprosy<sup>(29)</sup>. Its treatments are complex and still fragile in scientific evidence<sup>(30)</sup>. As expected, patients with advanced physical disability had more skin ulcers than patients with no disability. Since patients with advanced disability were independent in performing ADL, authors conclude that those ulcers are more linked to the progression of the disease rather than being eschars consequent from immobility.

Patients with leprosy commonly complain about pain<sup>(31-32)</sup>. Authors believed that subjects in advanced stages would suffer more pain as they have more skin ulcers. The findings here, however, were different: although the presence of ulcers is more frequent in the advanced stage of the disease, patients with severe disabilities presented less pain than patients with mild disabilities. Authors attribute this finding to the fact that anesthesia is common in advanced stages of the disease and sensory stimuli may not be felt by the patient.

Unlike the original hypothesis by the authors, patients with severe physical disabilities presented less neuropsychiatric symptoms than patients with mild physical disabilities. This may indicate, on one hand, that the disability degree alone is not capable of leading to inferences about the presence or absence of neuropsychiatric symptoms in patients with multibacillary leprosy. On the other hand, the results of neuropsychiatric tests could have been masked by an imprecise sense of health of patients

with severe disability, since the cognitive scores of participants of this group were relatively lower than the scores seen in the other groups. A complementary analysis showed that neuropsychiatric symptoms were more associated with age than with leprosy, leading authors to conclude that the neuropsychiatric symptoms were not affected by leprosy. This result goes against the study of Rocha-Leite and colleagues<sup>(33)</sup> and such divergence should stimulate new studies to better address this topic.

There have been controversies about whether people with leprosy suffer from dementia. Some studies show normal scores in patients with leprosy and others show cases of patients with dementia<sup>(13,34)</sup>. Most of patients assessed in this study presented normal scores in FAB and the values seen in the group of subjects with severe disabilities may indicate a cognitive decline, but not dementia<sup>(35)</sup>. In spite of the absence of differences between groups regarding cognition, the results indicate a tendency of cognitive decline as physical disability increases. Since the group with severe physical disabilities tended to be older than the other groups, correlation analyses confirmed that cognitive decline was more associated with aging than with leprosy.

### Limitations

Readers should be aware of some limitations in this study. First, the results are restricted to patients with multibacillary leprosy. Second, the severe disability group was significantly smaller than the groups with no disabilities or mild disabilities. Third, all patients were in use of medications for leprosy, which predisposes the findings to be restricted to medicated patients. Fourth, participants were not followed up after being discharged from the treatment<sup>(36)</sup>, making it difficult to analyze cause-effect inferences. Finally, the statistical correlations were of moderate magnitude<sup>(37)</sup>, indicating that there may be other factors not analyzed in this study impacting the variables.

### Contributions to the area

This manuscript brings new information about the care of people with leprosy. Physical disability, ADL, cognition, and neuropsychiatric disturbances are topics about which nurses, physicians, physical therapists, and other health care professionals should be aware before treating patients.

The results indicate the importance of providing early assistance to patients with multibacillary leprosy as a way to avoid physical disabilities and their impact on instrumental ADL. Authors believe that these findings shall stimulate new studies seeking to analyze internal and external factors that may affect the health of patients with leprosy.

### CONCLUSIONS

This study showed that physical disability is frequent in patients with multibacillary leprosy, as already reported in the literature. Participants were independent in performing basic ADL but presented difficulties in performing instrumental ADL. Cognitive decline and neuropsychiatric symptoms – although present – were more linked to aging than to leprosy.

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