

Limited activity and social participation after hospital discharge from leprosy treatment in a hyperendemic area in north Brazil

Pós-alta de hanseníase: limitação de atividade e participação social em área hiperendêmica do Norte do Brasil

Lorena Dias Monteiro^{I,II}, Carlos Henrique Alencar^{I,III}, Jaqueline Caracas Barbosa^I, Candice Cristiane Barros Santana Novaes^V, Rita de Cássia Pereira da Silva^{II}, Jorg Heukelbach^{I,IV}

ABSTRACT: Introduction: Neural damages are among the main factors that contribute to physical disability in leprosy. Systematic monitoring using a broad physical, psychological and social approach is necessary. **Objective:** The objective of this study was to characterize the limitation of activity and social participation and its correlation with disabilities and/or impairment in individuals after being discharged from a multidrug leprosy therapy. **Method:** A cross-sectional study conducted in Araguaína, state of Tocantins, which is a leprosy hyperendemic municipality. We included cases of patients who were discharged from treatment considered as cured from January 2004 to December 2009. We performed dermatological examination and applied the Screening Activity Limitation and Safety Awareness (SALSA) and social participation scales. **Results:** We included 282 individuals (mean age: 45.8 years old). The paucibacillary operational classification was more common (170; 60.3%). The eye-hand-foot score ranged from 0 to 12 (mean: 0.7). A total of 84 (29.8%) individuals presented limited activity. A slight restriction in social participation occurred in 18 (6.3%) cases. There was a statistically significant correlation between activity limitation, age ($r = 0.40$; $p < 0.0001$) and degree of functional limitation ($r = 0.54$; $p < 0.0001$), as well as of restricted social participation, activity limitation ($r = 0.56$, $p < 0.0001$) and functional limitations ($r = 0.54$, $p < 0.0001$). **Conclusion:** Functional limitation due to leprosy had an impact on the conduct of activities and social participation after the discharge from a leprosy treatment. The association between Screening of Activity Limitation and Safety Awareness and participation scales will assist in designing evidence-based assistance measures.

Keywords: Leprosy. Chronic limitation of activity. Social participation. Epidemiology. Scales. Disabled persons.

^IDepartamento de Saúde Comunitária da Faculdade de Medicina da Universidade Federal do Ceará – Fortaleza (CE), Brasil.

^{II}Fundação de Medicina Tropical do Tocantins da Secretaria de Estado da Saúde do Tocantins – Araguaína (TO), Brasil.

^{III}Swiss Tropical and Public Health Institute of University of Basel – Basel, Switzerland.

^{IV}Tropical Medicine and Rehabilitation Sciences, School of Public Health of James Cook University – Townsville, Australia.

^VInstituto Federal de Educação, Ciência e Tecnologia do Tocantins – Palmas (TO), Brasil.

Corresponding author: Jorg Heukelbach. Departamento de Saúde Comunitária da Universidade Federal do Ceará. Rua Professor Costa Mendes, 1608, 5º andar, Rodolfo Teófilo, CEP: 60430-140, Fortaleza, CE, Brasil. Email: heukelbach@web.de

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RESUMO: Introdução: Os danos neurais estão entre os principais fatores que contribuem para incapacidade física na hanseníase, então é necessário monitoramento sistematizado desses pacientes com abordagem ampla nos aspectos físicos, psicológicos e sociais. **Objetivo:** O objetivo deste trabalho foi caracterizar a limitação de atividade e participação social e sua correlação com incapacidades e/ou deficiências nas pessoas em pós-alta da poliquimioterapia para hanseníase. Método: Foi conduzido um estudo transversal no município de Araguaína, Tocantins, hiperendêmico para hanseníase. Avaliaram-se casos novos em alta por cura de janeiro de 2004 a dezembro de 2009, com realização de exame dermatoneurológico e análise da limitação funcional, de atividade e de restrição à participação social. **Resultados:** Foram entrevistadas e avaliadas 282 pessoas (média de idade: 45,8 anos). As formas clínicas paucibacilares foram mais frequentes (170 pessoas; 60,3%). O escore olho, mão e pé variou de 0 a 12 (média: 0,7). Um total de 84 (29,8%) pessoas apresentou limitação de atividade. A leve restrição à participação social foi mais frequente em 18 (6,3%) casos. Houve correlação estatisticamente significativa da limitação de atividade com idade mais avançada ($r = 0,40$; $p < 0,0001$) e com o grau da limitação funcional ($r = 0,54$; $p < 0,0001$), e da restrição à participação social com a limitação de atividade ($r = 0,56$; $p < 0,0001$) e com a limitação funcional ($r = 0,54$; $p < 0,0001$). **Conclusão:** A limitação funcional teve impacto sobre a realização de atividades e participação social das pessoas em alta da hanseníase. A associação entre os níveis de comprometimento nas escalas *Screening of Activity Limitation and Safety Awareness* e de participação pode subsidiar os profissionais na compreensão do comprometimento subjacente ao prestar assistência às pessoas atingidas.

Palavras-chave: Hanseníase. Limitação crônica da atividade. Participação social. Epidemiologia. Escalas. Pessoas com deficiência.

INTRODUCTION

In 2010, approximately 230 thousand new cases of leprosy were registered all over the world, and more than 13 thousand people presented with visible physical impairment at the time of diagnosis. In fact, leprosy is the main infectious disease that leads to permanent physical impairment^{1,2}. It is estimated that 2 million people have progressed to some kind of impairment since the implementation of polychemotherapy in 1980². In Brazil, even with the actions employed in the health services, leprosy is still a relevant public health issue³. It was the second country with more new detected cases, responsible for approximately 93% of the cases in the Americas⁴. Tocantins was the Brazilian state with the second highest general detection coefficient, with 72.14 new cases/100,000 inhabitants in 2010, and among people aged less than 15 years old, the detection coefficient was of 20.86/100,00 inhabitants⁵. The city of Araguaína, located in this State, is inserted in the most important group cases in the country, since it represents high risk for leprosy^{3,6}.

Data from the Ministry of Health in Brazil, from 2010, indicate that 7.2% of the assessed leprosy cases presented degree 2 of physical impairment at the time of diagnosis, and began treatment with some visible impairment in the eyes, hands and/or feet⁵. In this context, neurological damage is among the main factors that contribute with physical inability, which makes systematic monitoring necessary^{1,7}. However, there are important gaps in terms of operationalizing care to the people affected by leprosy at the post hospital discharge^{8,9}.

Many studies approach the matter of functional limitation of people affected by leprosy, but very little is known about the fear concerning impairment and/or stigma associated to the disease, which impact on the conduction of daily activities and the social participation of a person^{10,11}.

Besides, there is the need for health services to subsidize the management of leprosy with tools that assess not only the physical condition, in order to provide full attention and longitudinal care to this group of people^{8,9}.

This study aimed at characterizing the limitation of activities and social participation among people who had been discharged from polychemotherapy for leprosy in the city of Araguaína, Tocantins, thus correlating them to the different degrees of incapacities/physical impairment.

METHODS

This study is part of a larger project from *Universidade Federal do Ceará*, called INTEGRAHANS – MAPATOPI, based on an integrated approach of studies related to epidemiological, clinical, psychosocial and operational patterns of leprosy in the States of Maranhão, Pará, Tocantins and Piauí, with the financial support from the Department of Science and Technology (DECIT) from the Ministry of Health.

It is a cross-sectional study conducted in the city of Araguaína, north of the State of Tocantins, located in the Legal Amazon. The estimated population of the city was of 150,000 inhabitants in 2010, with approximate area of 4,000 km^{2,12}.

The target-population of the study consisted of all of the new cases of leprosy among people aged 15 years old or more who were discharged from treatment after being cured from January 2004 to December 2009, accounting for 693 people; discharge after cure was defined as the regular conclusion of polychemotherapy (PCT)⁵.

Participants answered a standardized interview and complementary information was obtained from the data base of the Information System on Disease Classification (SINAN) and from the medical records of health units where people affected by the disease were treated. Occupational activities were classified according to the Brazilian Classification of Occupations (CBO). The variables about gender, age, occupation, clinical form and eye-hand-foot scores were investigated.

The magnitude of incapacity at the time of diagnosis, expressed by the eye-hand-foot scores, was calculated based on the data collected during the simplified neurological evaluation. This score observes the sum of all of the degrees of individual incapacities referring both eyes, both hands and both feet, thus determining the maximum degree of incapacity for each affected segment, ranging from 0 to 12¹⁰.

In order to measure the limitation of activity among people impacted by leprosy, the Screening of Activity Limitation and Safety Awareness (SALSA) scale was used¹³. This scale is used to measure activity limitation and risk awareness due to deformities of people affected by leprosy, diabetes and other neuropathies. Its score ranges from 0 to 80, and higher scores indicate the increasing limitation for the performance of activities. 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)¹³. The risk awareness score is additionally calculated and ranges from 0 to 11, and higher values indicate more awareness of risks involving activities of daily living as a consequence of some activity limitation^{13,14}.

On the other hand, the participation scale approaches eight out of the nine domains of the component activity and participation of the International Classification of Functioning (ICF), which was used to measure the restriction to the social participation of the study population; its use is recommended in countries with endemic leprosy, and it is adequate to measure the restricted participation of people affected by leprosy who are older than 15 years old, because of impairment or other stigma. Composed of 18 items, scores range from 0 to 90. The levels of restriction are classified as: no restriction (0 to 12), mild restriction (13 to 22), moderate restriction (23 to 32), severe restriction (33 to 52) and extreme restriction (53 to 90)^{11,15,16}.

The software Stata 11[®] (Stata Corporation, College Station, USA) was used for data analysis. The analysis was based on data description and on the use of the Pearson's χ^2 test and dispersion graphs with correlation between the several calculated scores, 95% confidence intervals and 5% significance level.

The project was approved by the Research Ethics Committee of *Centro Universitário Luterano de Palmas*, Tocantins, (protocol n. 28/2009/CEP/ULBRA). Data collection was performed with the written consent of the participant (or legal representative) after the clarification of the research objectives.

RESULTS

The study included 282 individuals (40.7% of the target population). The total of 411 (59.3%) individuals who were not included was associated with: non location and/or changing addresses (287; 69.8%), nonattendance (69; 16.8%), refusal (31; 7.5%), others (25; 6.0%). Among the evaluated individuals, 145 (51.4% were male). The mean age was of 45.8 years old, ranging from 15 and 85 years old. More than half of the participants (171; 60.6%)

Table 1. Eye-hand-foot physical disability score, Screening of Activity Limitation and Safety Awareness score classification, risk awareness and restricted social participation of people with leprosy after hospital discharge in the period from 2004 to 2009, Araguaína, Tocantins.

Variables	n	%
Eye-hand-foot score		
0	199	70.6
1	22	7.8
2	32	11.3
3	9	3.2
4	10	3.6
5	2	0.7
6	3	1.1
7	2	0.7
8	2	0.7
9	-	-
10	-	-
11	-	-
12	1	0.3
SALSA scale score (1-80)		
No limitation (up to 24)	198	70.2
Mild limitation (25 to 39)	68	24.1
Moderate limitation (40 to 49)	11	3.9
Severe limitation (50 to 59)	3	1.1
Extreme limitation (60 to 80)	2	0.7
Risk awareness score		
0	214	75.9
1	43	15.2
2	13	4.7
3	4	1.4
4	3	1.1
5	2	0.7
6	1	0.3
7	2	0.7
8	-	-
9	-	-
10	-	-
11	-	-
Scale of social participation score (0-90)		
No significant restriction (0 to 12)	256	90.8
Mild restriction (13 to 22)	18	6.4
Moderate restriction (23 to 32)	5	1.8
Severe restriction (33 to 52)	1	0.3
Extreme restriction (53 to 90)	2	0.7
Total	282	100

SALSA: *Screening of Activity Limitation and Safety Awareness*.

were comprised of paid workers with activities defined by the Brazilian Classification of Occupations. Ninety six (34.0%) presented the indeterminate form, 74 (26.2%), tuberculoid, 75 (26.6%), dimorph, and 37 (13.1%), virchowian.

The maximum degree of physical incapacity (12 points), classified by the eye-hand-foot score, was observed in only one case. The others presented from 0 to 8 points, and 32 (11.3%) people presented at least two compromised segments (Table 1). The mean eye, hand and foot score was of 0.7, ranging from 0 to 12. Median was 0, with an interquartile interval between 0 and 1.

The mean SALSA score was of 4.8 points (SD = 7.84), ranging from 0 to 66 points. Median was 21, with interquartile interval between 19 and 26. The SALSA scale scores had different degrees of activity limitations, with scores equal or higher than 25 points in 84 (29.8%) people. The very severe limitation score was identified in 5 (1.8%) people. However, among people with limitations, the mild form was prevalent, with 68 (24.0%) cases.

The risk awareness score ranged from 0 to 7. However, the most frequent ones were 1 and 2, with 56 (19.9%) cases in total (Table 1). Median was 0, with interquartile interval from 0 to 0.

The mean score in the social participation scale was of 24.4 points (SD = 7.88, ranging from 16 to 68 points. Median was 2 (interquartile interval from 0 to 6). Among the cases that presented restriction to social participation, mild restriction was more common, with 18 (6.3%) cases (Table 1).

Activity limitation was significantly associated with older age in both operational classifications. In paucibacillary cases, positive correlation was considered to be moderate with age ($r = 0.40$; $p < 0.0001$), while in the multibacillary cases, correlation was lower ($r = 0.34$; $p = 0.0003$) (Figure 1).

There was a statistically significant association between activity limitation and functional limitation, and a moderate positive correlation was presented in paucibacillary ($r = 0.54$; $p < 0.0001$) and multibacillary cases ($r = 0.48$; $p < 0.0001$) (Figure 2).

Restriction to social participation (Figure 3) was significantly associated with activity limitation in both operational classifications ($p < 0.0001$), and presented moderate positive correlation in paucibacillary ($r = 0.56$) and multibacillary ($r = 0.55$) forms.

It was also observed that people with no restriction to social participation presented varied SALSA scores in paucibacillary and multibacillary cases. Severe restriction to social participation was observed in 1 (0.3%) person, with SALSA score between 50 to 59 and multibacillary classification. Extreme restriction to social participation occurred in 2 (0.7%) people, with SALSA score from 50 to 59 in the paucibacillary case and 25 to 39 in the multibacillary case (Figure 3).

Also, a significant association between restricted social participation and functional limitation was observed, which presents moderate correlation in the paucibacillary ($r = 0.54$; $p < 0.0001$) and multibacillary clinical forms ($r = 0.48$; $p < 0.0001$). Most evaluated people (256; 90.7%) did not present restrictions to social participation.

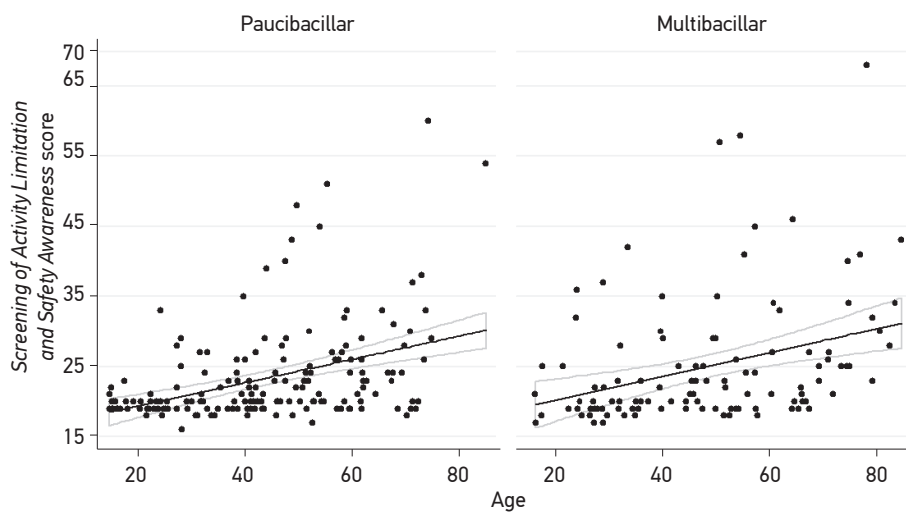


Figure 1. Correlation between Screening of Activity Limitation and Safety Awareness scores and age according to the operational classification of leprosy in people after hospital discharge in the period from 2004 to 2009, Araguaína, Tocantins.

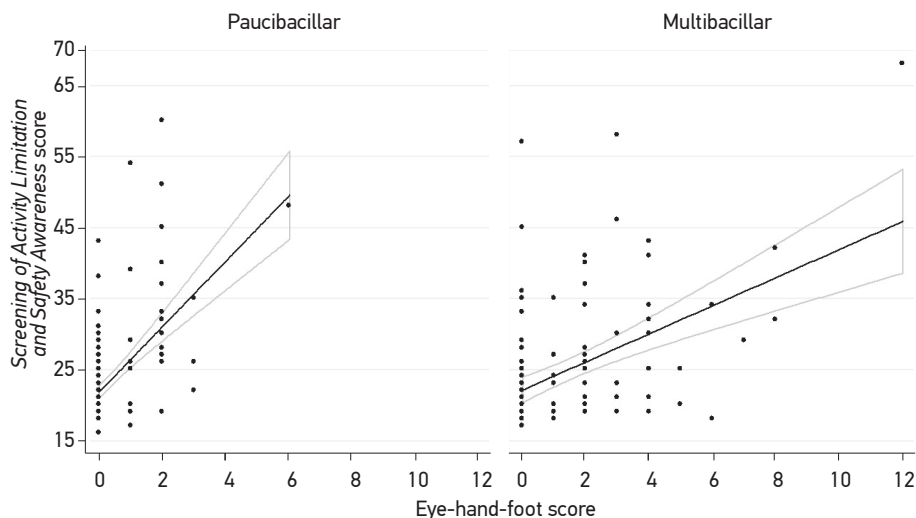
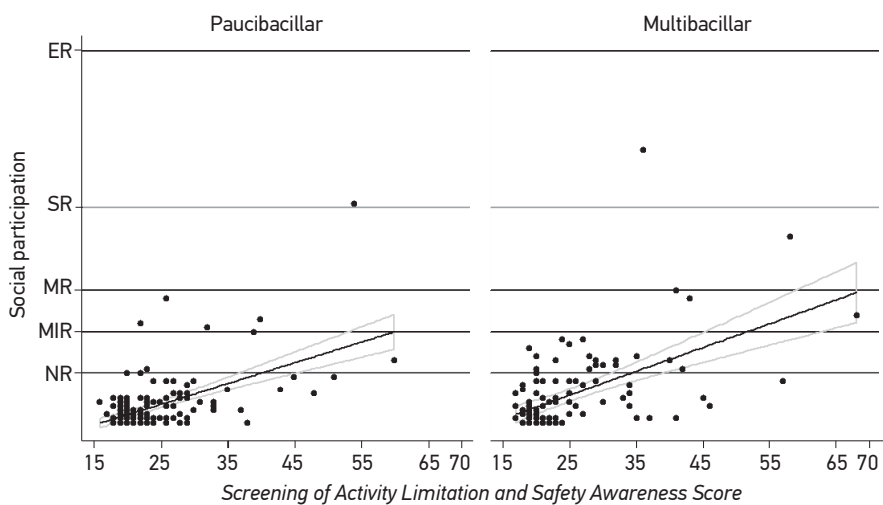
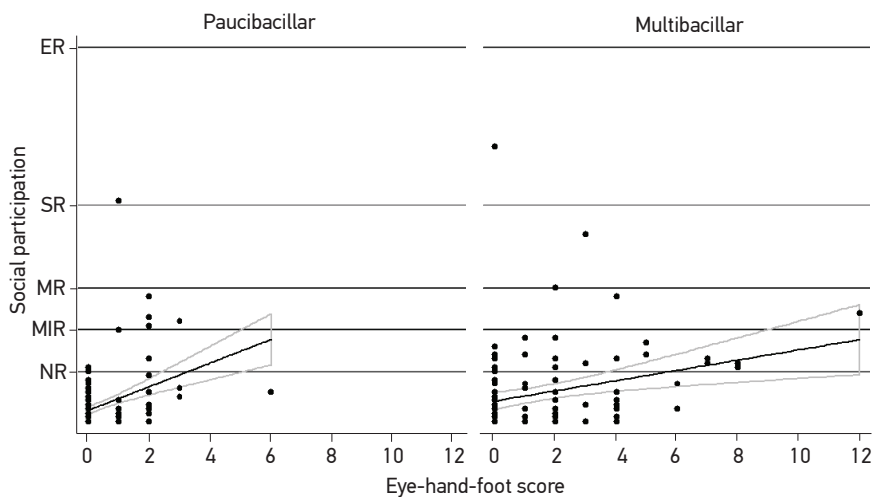


Figure 2. Correlation between the eye-hand-foot score and the Screening of Activity Limitation and Safety Awareness according to the operational classification of leprosy in people after discharge in the period from 2004 to 2009, Araguaína, Tocantins.



ER: extreme restriction; SR: severe restriction; MR: moderate restriction; MIR: mild restriction; NR: no restriction.

Figure 3. Correlation of social participation and Screening of Activity Limitation and Safety Awareness score according to the operational classification of leprosy in people after discharge in the period from 2004 to 2009, Araguaína, Tocantins.



ER: extreme restriction; SR: severe restriction; MR: moderate restriction; MIR: mild restriction; NR: no restriction.

Figure 4. Correlation of social participation and eye-hand-foot score according to the operational classification of leprosy in people after hospital discharge in the period from 2004 to 2009, Araguaína, Tocantins.

From these people, 194 (68.7%) had eye-hand-foot score equals to 0, and 26 (9.2%), from 1 and 12. Out of the two (0.7%) people with severe and extreme restriction to social participation, only one (0.3%) was classified as paucibacillar, and with eye-hand-foot score of three, while the other was classified as multibacillar, with eye-hand-foot score of zero (Figure 4).

DISCUSSION

In this study, screening by means of different internationally validated scales was able to identify significant levels of activity limitations and restriction to social participation among people affected by leprosy. Despite the great knowledge about impairment and physical inabilities associated with this chronic condition, there is still a major gap as to how they affect the performance of activities of daily living and social participation of a person who was discharged from treatment after being cured from leprosy^{10,11,15}.

A larger, proportion of paucibacillary cases was observed in the studied population, which indicates the correct diagnosis in local health services. This can be related to service factors, such as the integration of leprosy control actions in the services, facilitated access to care, as well as approach, information and health education for the population¹⁷. The verification of most cases at reproductive age becomes more important considering the impairing potential of the condition, which generates different types of impact in the social, economic, physical and psychological aspects¹⁸.

The eye-hand-foot score represented a more precise measure by classifying damage in different segments. It is recommended to identify the development of new or additional physical impairment in diagnosis, at hospital discharge and at post-hospital discharge, by comparing each moment with the objective of assessing the progression or the regression of inabilities^{19,20}. Its use enabled to obtain deep information about the degree of functional limitation in a person, and it proved to be more appropriate than the classification of the degree of incapacity to describe the extension of the incapacity condition among the assessed people¹⁹.

The proportion of cases with two or more compromised body structures was inferior to other Brazilian scenarios. However, early diagnosis was essential to prevent or minimize damage. Some studies pointed out to different proportions in several Brazilian scenarios, which ranged from 30.4 to 37.7% in the Northeast^{9,21}, and 66.7% in the Center-West²². In Nigeria and in the Netherlands, the proportion was of 78.6 and 83%, respectively^{23,24}.

The final score of the SALSA scale presented variation with different classifications of activity limitation, as observed in other scenarios^{8,9,22}. The mean of this score was relatively low when compared to recent data of Nigeria and Israel, where means of 27.4²³ and 29.1²⁵ points were reported, respectively. In this study, mild limitation was the most common one, however, little more than 5% of the people during post-hospital discharge

presented with moderate to very severe activity limitations, probably due to the functional limitation condition. This difference in relation to other studies can be explained by the epidemiological context, by the cultural aspects and by the different social/economic life contexts of these countries. In Brazil, health services develop leprosy-control actions, especially in the primary health care network, with the possibility of developing reference and counter-reference actions (to a higher or lower degree), with more complex services in the Unified Health System (SUS).

In general, participants presented with low-risk perception. The fact of not being able to physically perform a specific task determined many of the risk awareness situations, similarly to results from other studies^{8,9}. In case we were to establish the evaluation of the column in the SALSA scale concerning the “no, I avoid it because of the risk”, the awareness score would have been even lower.

Most people had no restrictions to social participation at the time of evaluation, probably because the most difficult moment to accept the disease happens during diagnosis and treatment^{8,9}. It was observed that less than 10% of the people who presented with mild restriction were men, with regard to items concerning work, since they considered the fact of not getting a job, not working the same number of hours and not contributing financially at home as much as their “peers” “to be a major problem”, which was caused or not by the fact of having had leprosy. Other studies identified a more frequent restriction (22.7%) possibly because it included people during treatment and at hospital discharge in the evaluation²².

From the people who presented severe and extreme restriction to social participation, two of them were related to leprosy. The other one corresponded to an older person who presented with neuromotor sequel caused by stroke. This person had no opportunities to have an active social life, since she lived in a nursing home for the elderly and lived only with the staff and the roommate.

The association between activity limitation with older age corroborates the nature of scales, since higher scores are frequently increasing with age²⁶. The moderate positive correlation found for paucibacillary cases can be explained as a consequence of the higher concentration of people with limitation from the age of 40 years old on. IN multibacillary cases, the correlation with age can be considered as weak, since the activity limitation was observed in very young people who had the advanced form of the disease, whose potential for physical inabilities and possible limitations in activities of daily living is bigger. In a previous study, the correlation between SALSA score and age was not so representative, with lower SALSA scores going through all of the age groups.

The association between activity limitation and functional limitation was a relatively expected situation. According to the validation of scales, the higher the functional limitation, the higher the activity limitation would be²⁶. The moderate positive correlation

for the clinical paucibacillary forms in the early stage of the disease called the attention. At this stage, inabilities were not expected to be so significant to the point of limiting activities of daily living of the affected individuals. In this context, there could possibly have been an error in operational classification. However, mild limitation was more frequent among the assessed cases, and affected mostly paucibacillary cases, which would explain a discreetly stronger correlation.

In the Philippines, visible deformities represented a risk factor for activity limitation among people affected by leprosy²⁷. The same could be observed in the Netherlands, where the severity of conditions was significantly correlated with activity limitations²⁴. In Brazil and in Bangladesh, people with functional limitation who were submitted to reconstructive surgery presented with significant improvement of activity limitation after a new evaluation^{28,29}. In another analysis, higher SALSA scores were significantly associated with deficiencies³⁰. In other studies, a correlation of physical inabilities with higher SALSA scores was observed. However, this relationship was partially observed in both studies, since people who presented 0 degree of physical incapacity obtained high SALSA score^{8,9,22}.

The scale of social participation presented statistically significant correlation with activity limitation, which is in accordance with the validation of scales¹⁶. However, in the correlation between the scale of participation and the SALSA score, it was observed that the total of people with no restrictions to social participation had several classifications in the SALSA score in the clinical paucibacillary and multibacillary forms. Therefore, it was possible to observe that the scale of participation, even when correlated to the SALSA scale, did not allow to conclude if the identified restriction is an exclusive result of leprosy, which leads to the need for further studies^{8,9,13}, or caused by matters of self-stigma, stigma and/or prejudice, in which people may present with some restriction to social participation and with low SALSA score, without limitation, for instance. A statistically significant correlation between social participation and functional limitation was also identified. This shows that deficiencies can physically restrict social participation skills. On the other hand, such individuals can suffer some sort of stigma. For instance, in the Philippines, individuals with visible impairment presented higher levels of participation restriction than those with other skin conditions²⁷.

It was also observed that approximately $\frac{1}{4}$ of the people with functional limitation did not present with restriction to social participation. Extreme restriction to social participation occurred in one of the people, since this person had history of depression. The other one was a consequence of leprosy, which led to extreme situations of prejudice and social isolation. The social participation of people with functional limitation improved with time in groups of people who underwent reconstructive surgery, but the difference was only significant in the group that did not undergo surgery²⁸.

Another analysis did not find any association between the scale of participation and physical inabilities³⁰.

Therefore, the application of the scale of participation does not allow to state that the identified restriction is exclusive for leprosy, and it is always important to know the context of the life of the assessed person⁸.

The limitation of this study was the non-inclusion of a larger number of people at post hospital discharge after being treated for leprosy for the reasons of not locating them and/or changing addresses (69.8%) and nonattendance (16.8%). Besides, there was error or lack of consistent information in SINAN and medical records.

People at the post hospital discharge presented with changes in functional limitation, activity limitation and restricted participation, which emphasizes the need for further studies about the impact of leprosy on the quality of life of these people.

CONCLUSION

In a hyperendemic city to the North of Tocantins, the functional limitation had a considerable impact on the performance of activities and the social participation of people who had been discharged from leprosy. The association between the levels of damage in the SALSA and participation scales may subsidize health professionals in order to understand the subjacent damage for treating people affected by leprosy. However, leprosy cannot be related singly causally to the restriction of social participation. The low perception of risk awareness pointed out to the need for orientation as to the domains of eyes, hands and feet.

The study also states that the potential of application of scales to quality the attention to patients with leprosy at the post hospital discharge, thus ensuring full attention, with broad approach in physical, psychological and social aspects. It reinforces that, even at the post hospital discharge, it is indispensable to conduct a systematic evaluation of the affected people in order to prevent incapacities and to promote the biopsychosocial rehabilitation by the health services.

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