Is the WHO disability grading system for leprosy related to the level of functional activity and social participation?

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Summary  To investigate the relationship between the WHO disability grading system for leprosy with the limitations to perform daily functional activities and the decrease in social participation in participants with leprosy.

Participants with a diagnosis of leprosy were recruited at the dermatology ambulatory clinic of the University Hospital of Sergipe. In order to investigate the association of WHO disability grading system for leprosy with activities of daily living measured with the Screening Activity Limitation and Safety Awareness (SALSA) scale and with the social participation (P-scale), we performed an analysis with the Kruskal-Wallis test and the Spearman coefficient.

Thirty-six patients diagnosed with leprosy participated in the study. Most of participants had mild to moderate daily activity limitations and 58% of participants did not have any restriction participation. The findings demonstrated that the WHO grading is associated with the level of activity ($P < 0.0001; \rho = 0.58$), but not with the level of participation ($P > 0.05; \rho = 0.27$).

Although the WHO grading system is used in Brazil and worldwide as an epidemiological indicator to explain the burden of leprosy, the results of this study demonstrated that in our sample the WHO grading system was not associated with participation. Participation is a complex construct with the influence of different psychosocial factors. In order to determine social participation damage of infectious diseases such as leprosy, it is necessary to develop new index of classification based
on a broader definition of disability. Health professionals should consider the international classification of function and health (ICF) to develop such index.

Keywords: Disability, Participation, Impairment, Activity, ICF

Introduction

Leprosy is still considered a public health problem in some countries, because of its high incidence and complications (physical impairment due to nerve damages, and psychosocial repercussions) associated to this disease. Interventions to effectively eliminate leprosy and reduce its consequences include early diagnosis, medical treatment, impairment prevention, as well as motor and psychosocial rehabilitation care.

According to the International Classification of Function, Disability and Health (ICF - WHO, 2001), disability can be defined as a difficulty in functioning at the body (biological), activity, personal (psychological aspects), environmental or societal (context and participation) levels, which can be experienced by an individual affected by a disease or a special health condition. The World Health Organization (WHO) classifies leprosy according to the WHO disability grading system, where Grade 0 means no impairment, Grade 1 means loss of sensation in the hand, eyes or foot, and Grade 2 means visible impairment. Leprosy impairment can also be quantified with the Eyes, Hands, Feet (EHF) score, a score combining indicators of physical impairment. The EHF Sum Score is obtained by adding the maximum grade for each of six body sites (eyes, hands and feet), and it can range from 0 to 12.

The WHO disability grading system for leprosy is simple and practical and it has been used as an epidemiological indicator to assess the efficacy of a public health programme. The inter-rater reliability for the grading test was reported as excellent when used by health specialists, with a Kappa coefficient 0.89 (95% CI, 0.84–0.94).

While being useful, the WHO disability grading classification system for leprosy has some limitations. One of those limitations is that it is not sensitive to change after treatment (considering that it is a three ordinal scale); therefore it cannot be used in rehabilitation practice to assess the effectiveness of a treatment, nor to evaluate general disability. As presented previously, the term disability includes more than just impairment, and, indeed, impairment is the main concept evaluated in the WHO grading system. In 2004, Nienhuis et al. suggested that the ‘WHO disability grading system’ should be renamed ‘WHO impairment grading system’, using the terminology defined by the ICF. Recently (2014), a Delphi list was formed to propose improvements in the WHO grading system.

Limitations in daily activities and restrictions to social participation are variables that need to be taken into account in analyses of the social and economic burden of leprosy, as well as in evaluations of the general disability or in the implementation of strategies aimed at the eradication of leprosy. The instruments currently available to evaluate these variables in patients with leprosy are the Scale of Activity Limitation and Safety Awareness and the Scale of participation. Previous studies have shown that patients with leprosy who were in treatment or after discharge presented limitations in the performance of some daily activities, which ranged from mild to severe. These studies also detected patients with restriction in social participation.
Certainly, the neuropathies caused by leprosy may give rise to physical impairments and diverse disabilities, especially for activities involving the use of hands, feet and eyes. Moreover, these disabilities may impact on social participation of affected individuals.\textsuperscript{11–13} However, it is not clear to what extent impairments can impact on the social participation of individuals with leprosy, since no previous study has investigated the association between the WHO grading system scores obtained with these patients, their level of activity measured with SALSA and their participation, measured with the Participation scale. Therefore, the objective of this study was to determine if the impairment grading classification system proposed by WHO is related with the performance of these patients in daily functional activities, as measured with the SALSA,\textsuperscript{14} and with their social participation (Participation scale).\textsuperscript{15}

**Methodology**

A cross-sectional design was used to investigate the association between the WHO disability grading system with activity (SALSA) and participation (Participation scale) measures.

**PARTICIPANTS**

Participants were recruited between May and November 2014 among ambulatory outpatients seen for the treatment of leprosy, leprosy reactions or sequels at the dermatology clinic of the University Hospital of Sergipe (Aracaju, Brazil), which is a reference service in leprosy care in the state of Sergipe. The following inclusion criteria were established: age over 18 years and score $\geq 26$ at the Modified Mini Mental State Exam (to avoid patients with cognitive deficits that might not understand or respond to the questionnaires). Subjects with arm or leg amputations not related to leprosy or diagnosis of other diseases resulting in physical disabilities (e.g., neurological or rheumatologic diseases) were excluded from the study.

Patients were characterised according to the type and clinical form of leprosy (paucibacillary or multibacillary; tuberculoid, lepromatous, undefined, pure borderline or neural). The degree of impairment was measured according to the simplified neurological assessment form of the WHO disability three grading system, which classifies the degrees as following: 0, no impairment in the eyes, hands and feet; 1, decrease or loss of sensation in the eyes, hands and feet; and 2, visible impairment.

The Ethic Research Committee of the Federal University of Sergipe had previously approved this study and all participants signed the consent form.

**MAIN OUTCOMES**

Activity was assessed with the Screening Activity Limitation and Safety Awareness scale.\textsuperscript{14} The SALSA measures limitations in activities and patients’ awareness towards the risks associated with diabetes mellitus, leprosy or other peripheral neuropathies. The SALSA scale consists of 20 items, based on the ICF activity domain. It is divided into areas related to mobility, self-care, work and dexterity, with scores ranging from 0 to 80; the higher the score, the greater are the activity limitations. If the final score is less than 25, it is considered that the subject does not have significant limitations in activity, whereas scores between 25–39 are
associated with mild limitations, 40–49 with moderate, 50–59 with severe and 60–80 with extreme limitations.\(^8\)

The limitations related to social participation were evaluated with the Participation scale,\(^15\) in which the participant has to compare his answers with those of a peer (someone whose condition is similar to him in all aspects except for illness or disability). The scale consists of 18 items addressing, for example, the possibility to find employment, job performance, mobility in public places and involvement in social activities. The scores range from 0 to 90, and are categorised in different levels of limitation: no significant limitation (0–12), mild (13–22), moderate (23–32), severe (33–52) or extremely severe (53–90) limitations.\(^8\)

**DATA ANALYSIS**

The SPSS Statistical Package for the Social Sciences version 23·0 (Chicago, IL) was used for statistical analysis. Descriptive statistics (mean, standard deviation, median and range) are reported for all analysed variables. To test if the data was normally distributed, a Kolmogorov-Smirnov test was performed. In order to evaluate the associations between the WHO grading system for impairment (ordinal data) and the activity limitation measured by the SALSA scale (continuous data), and between the WHO grading system and restriction to participation, as measured by the Participation scale (continuous data), a Kruskal-Wallis test and correlation analyses (Spearman coefficient) were performed.

**Results**

After screening, 40 participants were eligible to participate in the study. During the evaluation process, four of them were excluded: one participant was excluded because he could not understand some of the questions asked during the evaluation, and the three others were excluded because significant information was missing in their records (Figure 1). Participants’ demographic and clinical characteristics are presented in Table 1. The participant’s age, leprosy type and classification did not influence the results in activity and participation, with no association as investigated with separate analysis with the correspondent stratification of groups.

![Figure 1. Participants’ recruitment flowchart.](image-url)
ACTIVITY AND PARTICIPATION MEASURES

The results for activity, as measured with the SALSA scale, demonstrated that 33.3% of participants did not present significant activity limitation. A third of participants reported a mild limitation, while 14% were moderately limited, 11.1% severely limited and 8.3% showed extremely severe limitations (Figure 2a). Regarding restriction to participation, as measured with the Participation scale, the results indicated that 58% of participants did not have any restriction to participation, while 14% showed mild restriction, 8% moderate restriction and 20% severe restriction (Figure 2b).

DEGREE OF IMPAIRMENT × ACTIVITY AND PARTICIPATION

In order to explore possible associations between participants’ degree of impairment and limitations in activity or restriction to participation, we stratified the SALSA and Participation scores according to participants’ degree of impairment (from 0 to 2) (Table 2). A Kruskal-Wallis ANOVA was performed for SALSA and Participation scale values for each
degree of impairment. The SALSA scores were associated with the degree of impairment, $P < 0.01$, where high score on SALSA had higher impairment classification. However, no association was found between Participation scores and degree of impairment, $P > 0.05$ (Table 2).

To further quantify the association between impairment and activity, and impairment and participation, we performed a Spearman correlation test. The SALSA scale scores where highly correlated with the level of disability ($r = 0.58; P < 0.0001$; Figure 3a), but not with the Participation scores ($r = 0.27; P > 0.05$; Figure 3b).

**Table 2.** Results of SALSA scale and Participation scale in each degree of impairment

<table>
<thead>
<tr>
<th>Results</th>
<th>WHO disability three-grading system</th>
</tr>
</thead>
<tbody>
<tr>
<td>SALSA scale</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Grade 0 ($n = 10$)</td>
</tr>
<tr>
<td></td>
<td>21 (18–47)</td>
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<tr>
<td></td>
<td>Grade 1 ($n = 15$)</td>
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<tr>
<td></td>
<td>26 (20–60)</td>
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<tr>
<td></td>
<td>Grade 2 ($n = 11$)</td>
</tr>
<tr>
<td></td>
<td>40 (26–70)</td>
</tr>
<tr>
<td>Participation scale</td>
<td>Grade 0 ($n = 10$)</td>
</tr>
<tr>
<td>Social participation</td>
<td>4 (0–48)</td>
</tr>
<tr>
<td></td>
<td>Grade 1 ($n = 15$)</td>
</tr>
<tr>
<td></td>
<td>7 (0–47)</td>
</tr>
<tr>
<td></td>
<td>Grade 2 ($n = 11$)</td>
</tr>
<tr>
<td></td>
<td>16 (1–47)</td>
</tr>
</tbody>
</table>

Median, minimum and maximum; *Significant between-group difference at $P < 0.05$. 

**Figure 2.** (a) Results for activity limitation measured with the SALSA scale. (b) Restriction to participation measured with Participation scale.
Discussion

Leprosy is considered a neglected disease. While it is no longer a health problem in developed nations, it is still endemic in some African, Asian and Latin American developing countries.\textsuperscript{2,16} The fact that leprosy is particularly affecting populations with lower social status and level of education led researchers to investigate its association with psychosocial factors; these factors have been neglected in actual control and eradication programmes.\textsuperscript{17,18}
The application of ICF to leprosy offers new opportunities to evaluate its burden, as well as the mechanisms underlying its high incidence in middle and low-income countries. The currently available epidemiological data related to the classification of leprosy cases is mainly based on the WHO disability grading system, which solely evaluates the level of impairment, and do not take into account effects of the disease on social participation. The findings of this study demonstrated that the WHO disability grading system is associated with the level of activity (measured with the SALSA scale) in patients with leprosy, but not with the level of participation.

The ICF defines that impairment are problems in structure or body function such as significant deviation or loss of biological function. Activity is defined in the ICF concept as the execution of a task or action by an individual. And, participation is considered by the ICF as the involvement in a life situation. From these definitions, it is expected that activity measurements that are based on ICF’s definition of activity would be associated with impairment measurements. In the present study, the activity measurement was the SALSA scale, whose questions can be related to ICF’s definition. For example, SALSA’s questions such as “Can you see (enough to carry out your daily activities)?”, “Do you walk on uneven ground?”, “Do you open/close screw capped bottles?” are directly related to specific structures and functions of the body; therefore, it is expected that limitations in those activities would be associated with impairments. Our results, showing association between impairment and activity, are consistent with previous studies that demonstrated moderate to strong association between limitations of activity and impairments. Our results can be contrasted with those of a previous study involving elderly patients with leprosy that investigated the association between the WHO disability grading system and two activity types: basic activities of daily living (BADL) and instrumental activities of daily living (IADL). They found a weak association between the WHO disability grading system and IADL, and no association with BADL. The weakness of the association between grading of impairment and IADL might stem from the fact that questions used in the IADL scale (which was developed around 20 years before the ICF) address aspects related not only to activity, but also to participation. It should be noted that participation is a much more complex concept than activity, which does not only involve activity, but also life contexts such as environment and psychosocial aspects.

Indeed, in our study, participation levels were not associated with the WHO disability grading system. Social participation is a relatively new construct, which appeared during the revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH); it is highly influenced by environmental and cultural factors. In the latest definitions of activity and participation proposed by the ICF, participation is not only related to activity; it is also determined by contextual factors including environment and personal characteristics. For example, the individual with a disability due to leprosy can have the capacity to walk home; however, he avoids going to work because he does not want to take public transportation or show himself in public, being afraid of discrimination. Studies have demonstrated the correlation between participation restriction and stigma in patients with leprosy. Social stigma and discrimination are environmental factors that have significant impacts on the incidence and prevalence of leprosy, especially in developing countries, where most patients diagnosed with leprosy come from the poorest socioeconomic groups. In the present study, the results related to social participation demonstrated a high variability, with a wide range of scores, which contrasted with the narrow range of scores observed in the results related to activity limitations. Despite the high variability in
participation scores, our results can be compared to the others studies that identify participation as a complex construct related to environmental and personal factors and then not directly related to the degree of impairment.\textsuperscript{26–28} It will be interesting to investigate the relation of social participation and education, to understand if education determine in some way the level of social participation in individuals with leprosy.

In Brazil the WHO grading system is the most used measurement, it is used to classify impairment at the time of diagnosis and in the epidemiological notification. There is no doubt that the WHO grading system is a valid, reliable, practical and simple indicator to classify leprosy severity. However, the WHO grading system is based only on physical impairment. Therefore, many other dysfunctions can be underestimated when only the WHO grading system is applied, even social participation. Moreover, evaluating patients with leprosy only with the WHO grading system can harm the primary health assistance to refer patients to a more specialised treatments such as psychologists. In order to eradicate leprosy it is urgent and necessary to develop new classification indexes based on a broader definition of disability. The ICF could be used as a model to develop such an index.

**Limitations**

The results from this study should be interpreted within their limitations. Indeed, our sample was small and was local to the state of Sergipe, Brazil. Cultural and environmental aspects may play an important role in social participation.

**Conclusion**

The WHO disability grading system is associated with activity limitations in patients with leprosy, but not with restrictions to participation. Participation is a complex construct which is influenced by different psychosocial factors that can also impact health-seeking behaviours, which can have an impact on the control of the disease. The countries where leprosy is endemic are facing the challenge of making a more holistic report of problems experienced by patients; these reports should include not only the grade of impairment, but also assessments related to activity and participation, which are important variables in the design of efficient local public health strategies aiming to prevent and treat leprosy.

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