

## Physical disability and its social and functional repercussions in patients with leprosy after discharge from multidrug therapy

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### *Summary*

*Purpose:* This paper analysed the clinical characteristics, social insertion and functional limitations in patients with leprosy. They were evaluated in a university hospital in southeast Brazil between 1998 and 2013.

*Methods:* One hundred thirty six leprosy patients (aged 12–82 years) participated in a cross-sectional descriptive study after discharge from multidrug therapy treatment. Clinical and functional evaluations and characterisation of the restrictions to social involvement, through SALSA (Screening of Activity Limitation and Safety Awareness) and Participation Scales were performed.

*Results:* The patients (79 males, 57 females) mean age was  $44.67 \pm 15.05$  years. The major characteristics were male (79%), multibacillary (86%) and some disability (91.2%). 33.8% of the disabilities were graded 2. During the evaluation 56.5% of patients reported pain and 27.2% had used corticosteroid therapy. Ninety-five patients underwent neural decompression or tendon transfer surgery. Age below 64 years and pain represented a higher risk to activity limitation. According to SALSA and Participation Scores, 75% of patients had functional limitation and 52.2% social restriction.

*Conclusion:* Despite the context of a reference hospital, it is important to highlight the late diagnostics in this study. Our findings suggest that age over 64 was a protective factor for activity limitations, which may be related with a higher impact of the disease in the young, causing more limitations on activities. There was no association between SALSA score and the presence of deformity, demonstrating adaptation to physical disabilities. The treatment with MDT eradicates *M. leprae*, however it does not overcome the physical deformities already placed.

## Introduction

Leprosy is a chronic infectious disease that presents a spectrum of clinical manifestations defined by the patient's immune response.<sup>1</sup> It is characterised by the occurrence of mononeuritis multiplex, which may occur during one or many recurrent episodes of reactions of immunological origin that result in autonomic, sensory and motor neuropathy which become the main cause of physical disabilities.<sup>2,3</sup>

Physical disability is the most striking feature of leprosy, and continues to be a severe problem in public health programmes in endemic countries. The World Health Organization (WHO) defines the criteria for cure as regular administration of multidrug therapy (MDT) over 6 to 12 months. The number of patients handicapped during or after MDT has been an important public health problem, as leprosy is one of the most physically limiting diseases.<sup>4</sup>

In 2013, Brazil detected 31,044 new cases of leprosy. Of these, 27,364 cases were evaluated for disability, with 24.1% (6,607 cases) having Grade 1 and 7.2% (1,996 cases) having Grade 2 disability. Considering only the cases from that year, there are 8,603 cases of leprosy needing an integrated therapeutic approach, as well as requiring actions for the prevention of further disabilities, self-care and physical rehabilitation for those individuals.<sup>5</sup>

The deformities caused by leprosy can cause functional disability, as well as social discrimination and stigma, with severe psychological and social repercussions, that may lead to the formation of an environmental barrier for social participation.<sup>6-9</sup> Studies have highlighted the causal relationship between physical disability, restriction in social participation and functional limitation for leprosy patients after MDT discharge.<sup>12</sup>

Considering the disabling character and the stigma related to leprosy, it is necessary to develop an integrated approach to patients affected, regarding the bio-psychosocial aspects. Questions such as disability, limitation of activities and restriction of participation must be considered as fundamental and be evaluated during and, if possible, after the treatment.<sup>12,13</sup>

Regarding the elimination goal, as recognised by WHO and considering that the criteria of therapeutic discharge does not take into account the consequences already present or the ones that may yet develop after MDT discharge, referral centres for the prevention of physical disability such as the 'Hospital Universitário Clementino Fraga Filho (HUCFF)' from the Federal University of Rio de Janeiro (UFRJ) are essential. Those units should allow for the social and functional reintegration of people suffering from this disease. This hospital has developed, since 1998, the 'Project of Prevention and Physical and Surgical Rehabilitation in Leprosy,' involving professionals from Physiotherapy, Psychiatry, Orthopedics, Dermatology, Social Work, Occupational Therapy, Psychology and Neurology, as well as involving undergraduate and graduate students from the Federal University of Rio de Janeiro. The objectives of this study were to describe the clinical characteristics, functional and social limitations of patients referred to the HUCFF, over the period 1998 to 2013, due to physical complications and/or physical disability.

## Material and Methods

The study was approved by the Committee of Ethics in Research from the Secretaria Municipal de Saúdedo Rio de Janeiro, under record number 96/13. A cross-sectional descriptive study was developed in the HUCFF, a reference unit in the southeastern region of

Brazil. A convenience sample of 182 leprosy patients was studied corresponding to the case load at the hospital.

Inclusion criteria were: patients with leprosy, both genders, and older than 12 years old. Exclusion criteria were patients with other peripheral nerve diseases and cognitive deficits. Physical disability was evaluated by the 'degree of physical disability' and measured by a simplified neurological evaluation, as recognised by the Ministry of Health. This tool evaluates eyes, hands and feet using a 3 point scale (0, 1 and 2).

The Participation Scale was used to measure the social participation, whose domains are part of the International Classification of Disability and Health (ICF). It is a validated questionnaire, with 18 items quantifying the restrictions to participation experienced by leprosy patients and other disabling diseases. The scores range from 0 to 90 points. The cut-off to establish the presence of social restriction is 12 points. The classification of social restriction considers 13–22 as light restriction, 23–32 moderate restriction, 33–52 large restriction and 53–90 extreme restriction.<sup>9</sup>

The SALSA Scale was also developed based on ICF. It aims to evaluate the extent of activity limitation, an important tool to know how disability affects the daily life of people affected. The result of this evaluation is a score ranging from 0 and 80. Lower scores indicate fewer difficulties when performing daily life activities, while higher scores indicate growing levels of limitation (without limitation until 24; light limitation 25 to 39; moderate limitation 40 to 49; severe limitation 50 to 59; very severe limitation 60 to 80).<sup>14</sup>

Data collection was performed at HUCCF or in the patient's home, by the main researcher. Patients were invited by telephone to go to HUCCF in order to perform the evaluation. The phone call was made three times, on different days and times. Patients without a telephone for contact in the medical records were visited by the main researcher at their homes.

Data analysis was conducted with SPSS software, version 20.0. Data were expressed in tables by frequency (*n*) and percentage (%) according to the groups. The associations were studied with bivariate analysis of odds ratio (OR), confidence intervals of 95% and statistical significance  $P < 0.05$ .

Variable degrees of physical disability was categorised as 'presence of disability' (corresponding to individuals who, at the moment of evaluation, had Grade 1 or 2 disability) and 'absence of physical disability' (individuals that had Grade 0 disability). The Participation Scale was categorised as 'presence of restriction' (individuals that had light, moderate, large and extreme scores) and 'absence of restriction' (individuals that had score without restriction). The SALSA Scale was categorised as 'without limitation' (corresponding to individuals that had no limitation in daily life activities) and 'with limitation' (corresponding to individuals that had light, moderate, severe or very severe limitations in daily life).

We also studied the association between: (i) physical disability as an outcome and the socio-demographic, clinical and social restriction variables; (ii) the association between social participation as an outcome and socio-demographic, clinical and physical disability variables and (iii) functional limitation as an outcome and socio-demographic, clinical, physical disability and social restriction variables. Aiming to identify socio-demographic and clinical variables associated with the degree of physical disability, the Participation Scale and the SALSA Scale were assessed in  $\chi^2$  tests.

**Table 1.** Clinical characteristics of the sample

| Clinical characteristics | n   | %    |
|--------------------------|-----|------|
| Treatment                |     |      |
| PB                       | 19  | 14   |
| MB                       | 117 | 86   |
| Degree of disability     |     |      |
| 0                        | 12  | 8.8  |
| 1                        | 78  | 57.4 |
| 2                        | 46  | 33.8 |
| Corticosteroid           |     |      |
| Yes                      | 37  | 27.2 |
| No                       | 99  | 72.8 |
| Pain                     |     |      |
| Yes                      | 77  | 56.6 |
| No                       | 59  | 43.4 |
| Deformities              |     |      |
| Present                  | 53  | 38.9 |
| Absent                   | 83  | 61.1 |

## Results

Initially, a total of 182 cases were identified through the medical records; 136 patients (12 to 82 years old, average age of  $44.6 \pm 15.05$  years old), with 41.9% ( $n = 57$ ) females and 58.1% ( $n = 79$ ) males were evaluated. Prior to the study there were 46 losses, including 23 addresses not found, 14 changes of address to other cities, seven deaths and two with an incomplete address in the medical records.

From the evaluated patients ( $n = 136$ ), 86% had multibacillary and 14% (19) paucibacillary form. From those, at the moment of evaluation, 124 patients (91.2%) had some degree of disability (57.4% Grade 1 and 33.8% Grade 2), corticosteroid therapy (27.2%), and pain (56.5%). The characterisation of the population regarding the clinical profile is described in Table 1.

In Table 2, it is possible to observe the disability according to a stratified age group.

In this study, the 136 evaluated patients had impairment of 210 ulnar nerves (16.2% were unilateral and 69.1% bilateral); 209 median nerves (16.2% unilateral and 68.4% bilateral); 207 tibial nerves (15.4% unilateral and 68.4% bilateral); and 215 fibular nerves (19.9% unilateral and 69.1% bilateral).

**Table 2.** Distribution of disability according to age

|             | Disability |             | Total      |
|-------------|------------|-------------|------------|
|             | Absent     | Present     |            |
| 12–18 years | 2 (40%)    | 3 (60%)     | 5 (3.7%)   |
| 19–40 years | 5 (10%)    | 45 (90%)    | 50 (36.8%) |
| 41–60 years | 4 (6.7%)   | 56 (93.3%)  | 60 (44.1%) |
| > 60        | 1 (4.8%)   | 20 (95.2%)  | 21 (15.4%) |
| Total       | 12 (8.8%)  | 124 (91.2%) | 136 (100%) |

**Table 3.** Disability variable distribution according to gender, age and treatment

| Variables | Disability |            | OR   | CI         | p value |
|-----------|------------|------------|------|------------|---------|
|           | Absent     | Present    |      |            |         |
|           | n (%)      |            |      |            |         |
| Gender    |            |            |      |            |         |
| Male      | 5 (6.3)    | 74 (93.7)  | 0.48 | 0.14–1.60  | 0.227   |
| Female    | 7 (12.3)   | 50 (87.7)  |      |            |         |
| Age       |            |            |      |            |         |
| 12–64     | 12 (9.5)   | 114 (90.5) | 0.9  | 0.85–0.95  | 0.307   |
| >64       | 0 (0)      | 10 (100)   |      |            |         |
| Treatment |            |            |      |            |         |
| PB        | 1 (5.3)    | 18 (94.7)  | 1.86 | 0.22–15.36 | 0.555   |
| MB        | 11 (9.4)   | 106 (90.6) |      |            |         |

Ninety-five neural decompression surgeries were performed in 47 patients. Of those, 24 patients had 30 ulnar nerves decompressed (20 unilateral and five bilateral); 11 had median nerves decompressed, all unilateral (four right and seven left); 30 had 33 tibial nerves decompressed (27 unilateral and three bilateral) and 19 patients had 21 fibular nerves decompressed (17 unilateral and two bilateral).

Forty-five reconstructive surgeries were performed on 30 patients, 14 corrections of claw hand (one right, five left, four bilateral); nine corrections of claws in the digits of the feet (four right, three left and one bilateral); 16 corrections of drop foot (10 right and six left) and six surgeries for plantar ulcers (four right and two left).

According to Table 3 there were no significant differences in the distribution of the physical disability variable according to gender or age.

**Table 4.** Distribution of the socio-demographic and clinical variables according to the SALSA scale

| Variables | Limitation of activity (SALSA) |           | OR  | CI        | p value      |
|-----------|--------------------------------|-----------|-----|-----------|--------------|
|           | Absent                         | Present   |     |           |              |
|           | n (%)                          |           |     |           |              |
| Gender    |                                |           |     |           |              |
| Male      | 21 (26.6)                      | 58 (73.4) | 1.2 | 0.55–2.71 | 0.616        |
| Female    | 13 (22.8)                      | 44 (77.2) |     |           |              |
| Age       |                                |           |     |           |              |
| 12–64     | 28 (22.2)                      | 98 (77.8) | 0.2 | 0.05–0.72 | <b>0.008</b> |
| >64       | 6 (60)                         | 4 (40)    |     |           |              |
| Treatment |                                |           |     |           |              |
| PB        | 3 (15.8)                       | 16 (84.2) | 1.9 | 0.52–7.05 | 0.317        |
| MB        | 31 (26.5)                      | 86 (73.5) |     |           |              |
| Pain      |                                |           |     |           |              |
| Present   | 14 (18.2)                      | 63 (81.8) | 2.3 | 1.04–5.09 | <b>0.036</b> |
| Absent    | 20 (33.9)                      | 39 (66.1) |     |           |              |

**Table 5.** Distribution of the socio-demographic and clinical variables according to the Participation Scale

| Variables | Restriction of Social Participation |                  | OR   | CI        | <i>p</i> value |
|-----------|-------------------------------------|------------------|------|-----------|----------------|
|           | Absent<br>n (%)                     | Present<br>n (%) |      |           |                |
| Gender    |                                     |                  |      |           |                |
| Male      | 36 (45.6)                           | 43 (54.4)        | 0.8  | 0.40–1.59 | 0.541          |
| Female    | 29 (50.9)                           | 28 (49.1)        |      |           |                |
| Age       |                                     |                  |      |           |                |
| 12–64     | 58 (46)                             | 68 (54)          | 0.36 | 0.09–1.47 | 0.144          |
| >64       | 7 (70)                              | 3 (30)           |      |           |                |
| Treatment |                                     |                  |      |           |                |
| PB        | 8 (42.1)                            | 11 (57.9)        | 1.3  | 0.49–3.48 | 0.592          |
| MB        | 57 (48.7)                           | 60 (51.3)        |      |           |                |
| Pain      |                                     |                  |      |           |                |
| Present   | 36 (46.8)                           | 41 (53.2)        | 1.1  | 0.55–2.17 | 0.781          |
| Absent    | 29 (49.2)                           | 30 (50.8)        |      |           |                |

According to Table 4, those experiencing pain were more likely to have limitation of activity.

According to Table 5 there were no significant differences in the Participation Scale results according to the socio-demographic and clinical variables.

Tables 6 and 7 present the frequency of scores of the SALSA and Participation Scales.

In Table 8 no statistical significance was observed regarding the presence or absence of physical deformity according to scores of SALSA and Participation Scales in the evaluated patients.

## Discussion

The goal of eliminating leprosy established by the WHO, reachable due to the drastic decrease in world prevalence during the last 30 years, is related to and warranted by the implementation of MDT. Moreover, it is important to study the frequency of physical disabilities in a reference hospital in the area of physical and surgical rehabilitation in an endemic country such as Brazil. In our study, 91.2% of patients had some degree of disability. From those, 33.8% were classified as Grade 2.

It is important to note that this study was conducted in a referral hospital, which receives patients who generally already have some disability. Thus a higher degree of nerve

**Table 6.** Distribution of frequency of SALSA scores

| Variable               | N  | %    |
|------------------------|----|------|
| No limitation          | 34 | 25.0 |
| Mild limitation        | 40 | 29.4 |
| Moderate limitation    | 32 | 23.5 |
| Severe limitation      | 24 | 17.6 |
| Very severe limitation | 6  | 4.4  |

**Table 7.** Distribution of frequency of Participation Scale scores

| Variable                | N  | %    |
|-------------------------|----|------|
| No restriction          | 65 | 47.8 |
| Mild restriction        | 45 | 33.1 |
| Moderate restriction    | 13 | 9.6  |
| Severe restriction      | 12 | 8.8  |
| Very severe restriction | 1  | 0.7  |

impairment, disability, activity limitation and participation restriction may be expected as compared with studies of unselected leprosy patients. In the study of Brandão, we see that only 31% of patients post-discharge of Brazil have disabilities, but in our study this rate is 91%, because of the specific nature of the demand for a referral hospital.<sup>5</sup> At the hospital, the patient is evaluated and, if the disability is reversible, he/she is forwarded to the physical therapy department, where pre-surgery preparation is carried out. If the disability is not reversible, the patient is referred for occupational therapy with the goal of adapting the daily routine, with or without the use of orthotic devices. These interventions should be considered when analysing the results, especially in comparison with other studies where the patient was not referred to physical rehabilitation or surgical intervention.

Leprosy may affect body image and self-esteem. The stigma that goes with this disease may result in restriction of social participation.<sup>15,16</sup> Because of that, individuals need professional, family and social support.<sup>17</sup>

A relevant question to be evaluated is the perspective of the patient regarding the disease, the treatment, the perception of the need for care and limitations imposed from a personal, social and working point of view.<sup>18</sup> After discharge, many patients still need assistance due to the complications of the disease. However, the patients have few options when looking for care in the health sector, resulting in pain and insecurity.<sup>12,19</sup> In order to address those concerns, the HUCFF offers a monthly self-care group, a weekly group of art therapy, individual work with physical therapists and dermatologists besides clinical sessions with the interdisciplinary team in which hands and foot surgeons participate. Thus, considering that around 30–50% of patients with leprosy develop reactions and therefore are at risk of

**Table 8.** Distribution of the presence or absence of physical deformity variable according to the scores of SALSA and Participation Scales

| Variables        | Physical Deformity |                  | OR   | CI        | p value |
|------------------|--------------------|------------------|------|-----------|---------|
|                  | Absent<br>n (%)    | Present<br>n (%) |      |           |         |
| SALSA            |                    |                  |      |           |         |
| No limitation    | 22 (24.4)          | 68 (75.6)        | 0.91 | 0.40–2.07 | 0.834   |
| Some limitation  | 12 (26.1)          | 34 (73.9)        |      |           |         |
| Participation    |                    |                  |      |           |         |
| No restriction   | 44 (48.9)          | 46 (51.1)        | 1.13 | 0.55–2.32 | 0.721   |
| Some restriction | 21 (45.7)          | 25 (54.3)        |      |           |         |

complications, it is crucial that there is a systematic work-group allowing patients affected by leprosy to be reintegrated with their social and work environment.<sup>1,10,12,13</sup>

The literature highlighted evidence of associations between age, gender, clinical form, number of nerves affected in the beginning of treatment, degree of disability at the moment of diagnosis and bacteriological load as predictive factors for physical disabilities.<sup>20,21</sup> In 2007, after multivariate analysis, the study by Ranque *et al.* concluded that the only statistically significant risk factors for the occurrence of sequelae were sensorial or motor deficit and age, both for multibacillary as well as for paucibacillary patients.<sup>22</sup>

According to Sarkar, multibacillary patients have more disabilities than paucibacillary patients (31.6% vs 10%), in line with our data.<sup>23</sup> This finding was corroborated by other studies.<sup>24,25</sup>

This study revealed damage to more than one nerve in 96.3% of patients. The incidence of single neuritis in this population was 2.2%, smaller when compared to the findings of Penna reporting 11.8%.<sup>26</sup>

Our data revealed that there was no association between the SALSA score and the presence of deformity.<sup>1</sup> We believe that a possible reason could be the fact that patients already adapted to the deformity and did not see it as an obstacle for performing their daily activities normally. From the clinical point of view, it is expected that the elderly patient presents a lesser degree of activity, which may be another reason for the lower impact of disability as a cause for the limitation of activity. Other studies also found this lack of an association.<sup>13,27</sup> Regarding pain, our data revealed that patients with some complaints had twice the risk of activity limitation. It is worth highlighting though that this study was not about pain. The SALSA and Participation scales are validated tools, based on ICF, which examine the subject according to the biopsychological and social model, enabling a wider perspective regarding assistance.<sup>15</sup> In our study, 52.2% of the sample had some degree of restriction regarding social participation, higher than the findings of Castro, Singh *et al.* and Nardi, that had respectively 24.9%, 46% and 35% individuals with social restriction.<sup>10,12,28</sup> The finding in this study of 75% limitation of activity was higher than the one found by Nardi (57.8%).<sup>11</sup>

In 2009, Barbosa evaluated 304 patients in two cities from northeast Brazil, and observed that only 11% of individuals were above the cut-off on the Participation Scale (12 points).<sup>15</sup> Rafael observed that 53.33% of the 75 evaluated patients had some social restriction and that there was no association between the degree of physical disability and the scores on the Participation Scale.<sup>27</sup> This increased percentage found in Rafael's study may be explained by the fact that the Participation Scale was applied during MDT and, during this period, it may reflect the moment when the patient is more fragile and refusing to accept the diagnosis of the disease.

Decentralization of care to Primary Health Care units may allow for the continuity of access and care near the home. In order for this proposal to become a reality, it is necessary to invest in the process of continuing education for the technicians of the basic network, which may include training by various specialists, including the dermatologist and occupational therapist. This strategy moves from the specialist to the generalist thus increasing the capacity of Primary Health Care and establishing criteria for the flows of referrals and counter-referrals.<sup>12</sup>

The Participation Scale is fundamental during the MDT period, demonstrating all the feelings of the patient in reclusion, the fear and the anxiety due to the diagnosis. Otherwise,

we cannot infer that the social restriction suffered by this individual is exclusively due to leprosy. Thus, there is a need to qualitatively evaluate the context of the patient.

As limitations to this study, we may highlight the selective patient population, the cross-sectional nature of the study, the operational difficulties in finding the addresses of some patients during the home visits, the quality of the medical records that prevented the analysis of socio-demographic variables such as income and level of education and the absence of ocular evaluation.

As recommendations, we suggest the implementation of the SALSA and Participation Scales in routine health services during MDT treatment; the inclusion of muscle strength evaluation as a criterion for evaluating the degree of physical disability; the performance of prevention measures during routine self-care groups and measures of prevention, monitoring and rehabilitation of physical disabilities, concomitantly with the pharmacological treatment; and the intensification of training in 'preventive and reconstructive surgery in leprosy'. In the context of eliminating this endemic disease, it is essential to consider the demand after discharge from MDT regarding limitations of activities and restriction of social participation.

## References

- <sup>1</sup> Nascimento AMF. Avaliação da qualidade de vida, do desempenho nas atividades diárias e da consciência de risco das pessoas acometidas pela hanseníase após a alta da poliquimioterapia padrão OMS no município de Nova Iguaçu/RJ [Masters thesis]. Rio de Janeiro: Faculdade de Medicina: Universidade Federal do Rio de Janeiro; 2012.
- <sup>2</sup> Van Brakel WH. Peripheral neuropathy in leprosy and its consequences. *Lepr Rev*, 2000; **71(supplement)**: S146–S153.
- <sup>3</sup> Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância Epidemiológica. Manual de Prevenção de Incapacidades. 3ª ed., rev. e amp. – Brasília, DF; 2008.
- <sup>4</sup> Rafferty J. Curing the stigma of leprosy. *Lepr Rev*, 2005; **76**: 119–126.
- <sup>5</sup> Brandão JG. Electronic Publication [personal message]. Message received by <gomes.mariakatia@gmail.com> in Jan.14th, 2015.
- <sup>6</sup> Van Brakel WH, Sihombing B, Djarir H *et al*. Disability in people affected by leprosy: the role of impairment, social participation, stigma and discrimination. *Glob Healthy Action*, 2012; **5**: 1–11.
- <sup>7</sup> Boku N, Lockwood DNJ, Balagon MV *et al*. Impacts of the diagnosis of leprosy and of visible impairments amongst people affected by leprosy in Cebu, the Philippines. *Lepr Rev*, 2010; **81**: 111–120.
- <sup>8</sup> Stevelink SA, van Brakel WH, Augustine V. Stigma and social participation in Southern India: Difference and commonalities among person affected by leprosy and persons living with HIV/AIDS. *Psychology, Health and Medicine*, 2011; **16**: 695–707.
- <sup>9</sup> van Brakel WH, Anderson AM, Mutatkar RK *et al*. The Participation Scale: measuring a key concept in public health. *Disab Rehabilitation*, 2006; **28**: 193–203.
- <sup>10</sup> Nardi SM, Paschoal VD, Zanetta DM. Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev*, 2011; **82**: 55–64.
- <sup>11</sup> Nardi SM, Paschoal VD, Zanetta DM. Limitations in activities of people affected by leprosy after completing multidrug therapy: application of the SALSA scale. *Lepr Rev*, 2012; **83**: 172–183.
- <sup>12</sup> Castro LE, da Cunha AJLA, Fontana AP *et al*. Physical disability and social participation in patients affected by leprosy after discontinuation of multidrug therapy in Brazil. *Lepr Rev*, 2014; **85**: 208–218.
- <sup>13</sup> Barbosa JC, Ramos Junior NA, Alencar MJF *et al*. Pós-alta em hanseníase no Ceará limitação da atividade funcional, consciência de risco e participação social. *Revis Bras Enferm*, 2008; **61**: 727–733.
- <sup>14</sup> SALSA COLLABORATIVE GROUP. 2000: Jannine Ebenso (TLM Nigéria), Priscila Fuzikawa (Brasil), Hanna Melchior e Ruth Wexler (Hospital Hansen, Israel), Chen Shumin (CDC Shan Dong, China), Angelika Piefer (TLM, Singapura), Raj Premkumar (SLR&TC, Índia), Catherine Benbow (Reino Unido), Peter Nicholls (Univ. de Aberdeen, Reino Unido), Johan Velema (TLM International), Paul Saunderson (ALM, Estados Unidos), Linda Lehman (ALM, Brasil); 2000.
- <sup>15</sup> Barbosa JC. Pós-alta em hanseníase no Ceará: olhares sobre políticas, rede de atenção básica à saúde, limitação funcional, de atividades e participação social de pessoas atingidas [PhD thesis]. Universidade de São Paulo; 2009.
- <sup>16</sup> Aquino DMC, Caldas AJM, Silva AAM *et al*. Perfil dos pacientes com hanseníase em área hiperendêmica da Amazônia do Maranhão, Brasil. *Revista da Sociedade Brasileira de Medicina Tropical*, 2003; **36**: 57–64.

- <sup>17</sup> Franco TB, Merhy EE. El reconocimiento de la producción subjetiva del cuidado. *Salud Colect*, 2011; **7**: 9–20.
- <sup>18</sup> Higgison IJ, Carr AJ. Measuring quality of life: using quality of life measures in the clinical setting. *BMJ*, 2001; **322**: 1297–1300.
- <sup>19</sup> Amorim DGO, Waltrick CR, Wendhausen A. Participação: possibilidade na busca da cidadania para o portador de hanseníase? *Texto Contexto Enferm*, 1998; **7**: 328–344.
- <sup>20</sup> Gonçalves SD, Sampaio RF, Antunes CMF. Fatores preditivos de incapacidades físicas em pacientes com hanseníase. *Rev Saúde Pública*, 2009; **43**: 267–274.
- <sup>21</sup> Chen S. Prevalence and characteristics of neuropathic pain in the people affected by leprosy in China. *Lepr Rev*, 2012; **83**: 195–201.
- <sup>22</sup> Ranque B. Age is an important risk factor for onset and sequelae of reversal reactions in Vietnamese patients with leprosy. *Clin Infect Dis*, 2007; **44**: 33–40.
- <sup>23</sup> Sarkar J. Disability among new leprosy patients, an issue of concern: an institution based study in an endemic district for leprosy in the state of West Bengal, India. *Indian J Dermatol Venereol Leprol*, 2012; **78**: 328–334.
- <sup>24</sup> Silva SF, Griep RH. Reação hansênica em pacientes portadores de hanseníase em centros de saúde da área de planejamento 3.2 do município do Rio de Janeiro. *Han Intern*, 2007; **32**: 155–162.
- <sup>25</sup> Richardus JH. Incidence of acute nerve function impairment and reactions in leprosy: a prospective cohort analysis after 5 years of follow-up. *Int J Epidemiol*, 2004; **33**: 337–343.
- <sup>26</sup> Penna GO. A clinical trial for uniform multidrug therapy for leprosy patients in Brazil: rationale and design. *Mem Inst Oswaldo Cruz*, 2012; **107(Suppl.1)**: 22–27.
- <sup>27</sup> Rafael AC. Pacientes em tratamento e pós alta da hanseníase: estudo comparativo entre os graus de incapacidades preconizados pelo Ministério da Saúde correlacionando-os com as escalas SALSA e participação [Masters thesis]. Universidade de Brasília; 2009.
- <sup>28</sup> Singh S, Sinha AK, Banerjee BG *et al*. Participation level of the leprosy patients in society. *Indian J Lepr*, 2009; **81**: 181–187.