

Epidemiology and assessment of the physical disabilities and psychosocial disorders in new leprosy patients admitted to a referral hospital in Belo Horizonte, Minas Gerais, Brazil

SILVIA H. L. MOURA***, MARIA APARECIDA F. GROSSI***, LINDA F. LEHMAN****, STEPHANIE P. SALGADO**, CAROLINA A. ALMEIDA**, DAGMAR T. LYON**, SANDRA LYON** & MANOEL O. C. ROCHA*

**Programa de Pós-Graduação em Ciências da Saúde, Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil*

***Serviço de Dermatologia Sanitária, Hospital Eduardo de Menezes, Fundação Hospitalar do Estado de Minas Gerais (FHEMIG), Belo Horizonte, MG, Brazil*

****Coordenação Estadual de Dermatologia Sanitária, Secretaria Estadual de Saúde de Minas Gerais, Belo Horizonte, MG, Brazil*

*****American Leprosy Missions, Belo Horizonte, MG, Brazil*

Accepted for publication 27 March 2017

Summary

Objective: Despite intensive campaigns initiated in the 1990s, leprosy remains endemic in Brazil. It is essential that simple and efficient methods of assessing the extent of disease-related disabilities be established so that appropriate treatment and rehabilitation can be provided to patients in order to break the disease transmission chain.

Method: The socioeconomic, clinical, and physical/psychosocial disabilities of 56 new leprosy patients admitted to a referral hospital in Belo Horizonte, Minas Gerais, were assessed using available rating scale tools namely, WHO Impairment Grade (IG), Eye-Hand-Foot (EHF) Impairment Sum, Green Pastures Activity Scale (GPAS), Screening of Activity Limitation and Safety Awareness (SALSA), Participation, Jacoby stigma and Hamilton depression scales.

Results: Approximately 60% of the patients exhibited Grade 1 or 2 physical disabilities, 46% presented activity limitations and lacked safety awareness, around 30% presented difficulties in social interaction and perceived leprosy-related stigma and about 60% exhibited some degree of depression.

Conclusions: Continuation of intensive educational campaigns in schools, administration of proper medical and psychological care to patients with disfigurement/deformities and reevaluation of the role of specialised referral hospitals will be required if leprosy is to be removed from the list of public health diseases in Brazil.

Keywords: Hansen's disease, Leprosy-related disabilities, Rating scores

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, a gram-positive intracellular parasite found mainly in warm, tropical regions, and constituting a serious public health problem in various parts of the world. In 1990, the World Health Organization (WHO), in association with the health authorities of endemic countries and territories that were endemic for leprosy, initiated an intensive campaign aimed at reducing the prevalence of the disease to less than one case per 10 000 inhabitants. As part of the strategy, WHO recommended treatment involving multi-drug therapy (MDT), the supply of which should be free of cost to leprosy patients in all endemic countries.

The campaign has generally been successful and most countries that were previously highly endemic for the disease have achieved the elimination target. However, endemic foci of leprosy remain in a few countries, one of which is Brazil where the national prevalence rate was 1.42 cases per 10 000 inhabitants in 2013. Although the prevalence is below the WHO target in some southern and southeastern states of the Federation, including, for example, Minas Gerais with 0.51 cases per 10 000 inhabitants, the disease remains widespread in the rest of the country and the rate remains particularly high in the states of Mato Grosso, Maranhão and Tocantins with 9.03, 5.29 and 4.28 cases per 10 000 inhabitants, respectively.¹

Leprosy-induced disabilities are not confined to physical impairment and disfigurements or deformities, but also encompass limitation of activity, discrimination, stigma and restriction in social participation.² Moreover, such disabilities often remain even after successful MDT, although the degree to which this occurs can vary widely between different centers according to the type of leprosy, the demographic characteristics of the patient and the classification system used to assess the disabilities. In this context, a number of different rating systems are available and these include the WHO Maximum Impairment Grade (IG),³ the Eye-Hand-Foot (EHF) impairment sum score,⁴ the Screening of Activity Limitation and Safety Awareness (SALSA) scale,⁵ the Green Pastures Activity Scale (GPAS)⁶ and the Participation scale.⁷ Moreover, two non-conventional measures that have been developed for other medical conditions, namely the Jacoby Stigma scale⁸ and the Hamilton Depression scale,⁹ could be applied in the assessment of leprosy-induced disabilities.

Rating the physical and psychosocial statuses of leprosy patients is important in formulating and managing the care and rehabilitation of individuals with different types of disabilities, and in evaluating the effectiveness of the treatment applied. Thus, the objectives of the present study were: (i) to determine the epidemiological profiles of new leprosy patients admitted to a referral hospital in Belo Horizonte, MG, Brazil, during January 2009 and October 2010; (ii) to estimate the total frequency of physical and psychosocial disabilities using different rating systems; (iii) to identify the most adequate rating scale for routine use in basic health units and in referral hospitals at the time of diagnosis, during and after treatment; and (iv) to propose strategies for improving leprosy management and control.

Methods

ETHICAL ISSUES

The study was approved by the Ethical Committee of the Hospital Eduardo de Menezes (protocol no. 0034.0.203.000-10), which is administered by the Fundação Hospitalar do Estado de Minas Gerais, Belo Horizonte, MG, Brazil, and was conducted according to the principles of the Declaration of Helsinki. The aims and objectives of the investigation were explained carefully to all potential participants, who were then invited to take part in the study and sign the document of written informed consent.

PARTICIPANTS

This descriptive, cross-sectional epidemiological study comprised 56 new leprosy patients admitted directly to the Serviço de Dermatologia Sanitária in the Hospital Eduardo de Menezes or referred from other institutes or hospitals during the period January 2009 and October 2010. The exclusion criteria were: (i) children aged < 10 years, (ii) patients who had already received treatment for the condition at the commencement of the study, and (iii) subjects presenting speech, hearing or cognitive impairment. The required sample size was calculated on the basis of a previous pilot study involving 15 individuals and considered a confidence level of 95% ($\alpha = 0.05$) and a power of 80% ($\beta = 0.20$).

PROCEDURES

Socio-demographic and clinical data of the patients were obtained from the medical records provided by the Hospital Eduardo de Menezes (primary source) and from notification forms provided by the Sistema Nacional de Agravos e Notificação (secondary source).¹⁰

Physical disabilities were assessed using the IG and EHF forms provided by the Brazilian Ministry of Health, the validated Portuguese-language version of the SALSA scale, and a Portuguese version of the GPAS scale, the translation of which had been verified by one of the native English-speaking authors (LL). The psychosocial disabilities were assessed using Portuguese-language versions of the Participation, Hamilton depression and Jacoby stigma scales (this last scale was translated by the authors). All scales were applied by trained health professionals.

DATA ANALYSIS

Data were digitalised with the aid of Epidata software version 3.1 for Windows (Epidata Association, Odense, Denmark) and subsequently processed using SPSS software version 17.0 for Windows (SPSS Inc., Chicago, IL, USA). Frequencies of occurrence were expressed as percentages of the total population ($N = 56$).

Results

SOCIODEMOGRAPHIC CHARACTERISTICS OF PATIENTS

The majority of leprosy patients in the study population (Table 1) were male (57.1%) and most were aged between 31 and 60 years (62.5%). However, 10.6% of leprosy patients were

Table 1. Sociodemographic characteristics, assessed at the time of diagnosis, of leprosy patients ($n = 56$) referred to the Hospital Eduardo de Menezes, Belo Horizonte, MG, Brazil, during the period January 2009 to October 2010

Parameter	<i>n</i> (%)	Parameter	<i>n</i> (%)
Gender		Origin	
Male	32 (57.1)	Centre of MG	52 (92.8)
Female	24 (42.9)	Centre-west of MG	2 (3.6)
Age		North of MG	2 (3.6)
10–15	6 (10.6)	Area of residence	
16–20	3 (5.4)	Urban	53 (94.6)
21–30	4 (7.2)	Rural	2 (3.6)
31–40	19 (34.0)	Non specified	1 (1.8)
41–50	4 (7.2)	Marital status	
51–60	12 (21.3)	Single	17 (30.4)
61–70	7 (12.5)	Married	30 (53.5)
71–80	1 (1.8)	Cohabiting	5 (8.9)
Skin color		Separated	2 (3.6)
White	21 (37.5)	Divorced	1 (1.8)
Black	7 (12.5)	Widow	1 (1.8)
Brown	28 (50.0)	Occupation	
Education		Temporary out-of-work	6 (10.6)
Illiterate	5 (8.9)	Retired	4 (7.2)
Primary schooling	32 (57.1)	Unemployed	4 (7.2)
Secondary schooling	7 (12.5)	Employed	42 (75.0)
University	2 (3.6)		
Not specified	10 (17.9)		

youths within the age range 11 to 15 years. The distribution of leprosy patients according to the inherited physical trait of skin color revealed a higher preponderance among black- and brown-skinned participants (62.5% overall) compared with their white-skinned counterparts. In the present study, two-thirds of the new leprosy patients were either non-readers or had only primary schooling, and the majority lived in urban settings (94.6%), were married (53.5%) and employed (75%).

CLINICAL CHARACTERISTICS OF PATIENTS

As shown in Table 2, the frequencies of patients with borderline or borderline lepromatous forms of the disease (92.8%) and those with five lesions or more (57.1%) were high. Furthermore, 94.6% of the patients were classified as multibacillary (MB) and only 5.4% as paucibacillary (PB), while 44.7% reported Type 1 and 25% reported Type 2 reactions.

PHYSICAL DISABILITIES AND ACTIVITY LIMITATIONS OF PATIENTS

According to the IG rating system, 58.9% of the new leprosy patients exhibited physical disabilities of Grades 1 or 2, with the frequency of the latter (most severe) being 16% (Table 3). Similarly, the EHF scores determined at the time of diagnosis showed that the frequency of patients with physical disabilities (61%) was high and the mean score was 1.55.

The SALSA scale of activity limitations revealed that 35.8% of new leprosy patients encountered little difficulty with the activities of daily life (mild limitation), while 10.7% expressed increased difficulty (moderate to severe limitation) at the time of diagnosis (Table 3). Furthermore, 55.4% of the patients were unaware of any risky activities, whereas

Table 2. Clinical characteristics, assessed at the time of diagnosis, of leprosy patients ($n = 56$) referred to the Hospital Eduardo de Menezes, Belo Horizonte, MG, Brazil, during the period January 2009 to October 2010

Parameter	<i>n</i> (%)	Parameter	<i>n</i> (%)
Detection of leprosy		Clinical form	
Referral	41 (73.2)	Indeterminate	1 (1.8)
Spontaneous help sought	9 (16.1)	Tuberculoid	3 (5.4)
Clinical examination	4 (7.1)	Borderline	40 (71.5)
Others	2 (3.6)	Borderline lepromatous	12 (21.3)
Onset of symptoms (months)		Multi-drug therapy	
0–12	30 (53.5)	PB	2 (3.6)
13–24	12 (21.3)	MB	46 (82.1)
25–35	4 (7.2)	Alternative	8 (14.3)
36–47	4 (7.2)	Type 1 reaction episodes	
48–60	1 (1.8)	Absent	31 (55.3)
>60	2 (3.6)	Lesion exacerbation	3 (5.3)
Unknown	3 (5.4)	Neuritis	20 (35.8)
Bacilloscopy		Lesion/neuritis exacerbation	2 (3.6)
Negative	30 (53.5)	Type 2 reaction episodes	
Positive	23 (41.1)	Absent	42 (75.0)
Not specified	3 (5.4)	Erythema nodosum	8 (14.2)
Number of lesions		Hand and feet reaction	1 (1.8)
≤5	24 (42.9)	Orchitis	1 (1.8)
>5	32 (57.1)	Erythema nodosum/multiform	3 (5.4)
Classification of leprosy		Erythema nodosum/orchitis	1 (1.8)
Paucibacillary (PB)	3 (5.4)		
Multibacillary (MB)	53 (94.6)		

19.6% showed a very low level of risk perception and the remaining 25% showed an increasing awareness of injurious activities. The results obtained through application of the GPAS scale indicated that 32.1% of new leprosy patients experienced mild activity limitation, while 16.1% were moderately or severely affected by leprosy.

PSYCHOSOCIAL DISORDERS OF PATIENTS

The types of psychosocial disorders that afflicted the new leprosy patients admitted to Hospital Eduardo de Menezes are presented in Table 4. According to the Participation scale, 69.8% of the new leprosy patients had encountered no restrictions on social involvement, whereas 19.5% of them had experienced insignificant or mild restrictions and 10.7% stated that the disease imposed moderate to severe/extreme restrictions on social participation.

Application of the Jacoby stigma scale to the new leprosy patients showed that 32.1% had experienced stigma at the time of diagnosis, while the Hamilton depression scale revealed that 50% of the patients presented mild to moderate depression and 8.9% exhibited severe depression.

Discussion

DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF NEW LEPROSY PATIENTS

The predominance of males in the study population is in accordance with data released by the Brazilian Ministry of Health¹ for cases notified in 2013 at both national (56.6% males)

Table 3. Frequency of physical disabilities, assessed at the time of diagnosis, of leprosy patients ($n = 56$) referred to the Hospital Eduardo de Menezes, Belo Horizonte, MG, Brazil, during the period January 2009 to October 2010

Grade or score (rating scale)	Frequency	%
Body function and structure (IG grade) ^a		
Grade 0	23	41.1
Grade 1	24	42.9
Grade 2	9	16.0
Body function and structure (EHF score) ^b		
Score 0	22	39
Score 1	10	17.9
Score 2	11	19.8
Score 3	5	8.9
Score 4	4	7.2
Score 5	1	1.8
Score 6	2	3.6
Score 7	1	1.8
Activity limitation (SALSA scale) ^c		
None	30	53.5
Mild	20	35.8
Moderate	5	8.9
Severe	1	1.8
Safety awareness (SALSA scale) ^c		
Score 0	31	55.4
Score 1	11	19.6
Score 2	5	8.9
Score 3	5	8.9
Score 4	2	3.6
Score 5	2	3.6
Activity limitation (GPAS)		
None	29	51.8
Mild	18	32.1
Moderate	4	7.2
Severe	5	8.9

^aMaximum WHO Impairment Grade (IG) - Scores: 0 = no anesthesia, no visible deformity or damage to hands or feet, no leprosy-related eye problems, no evidence of visual loss; 1 = anesthesia, but no visible deformity or damage to hands or feet, vision not severely affected ($\geq 6/60$); 2 = visible deformity or damage to hands or feet, severe visual impairment ($\leq 6/60$), lagophthalmos, iridocyclitis, corneal opacities.

^bEye-Hand-Foot Impairment (EHF) score: the scores derive from the sum of the IG scores for each eye, each hand and each foot and range from 0 to 12.

^cScreening of Activity Limitation and Safety Awareness (SALSA) scale. The scores of the safety awareness component of the scale range between 0 and 11. The higher scores indicate an increasing awareness of the risks of certain activities.

^dGreen Pastures Activity Scale (GPAS).

and state (59.6% males) levels. A less remarkable preponderance of leprosy among male patients (51.7%) has also been recorded in São Luis (Maranhão).¹¹ The gender difference in leprosy can be explained by biological, economical and socio-cultural behaviors, since men are not only more exposed to the risks of infection by virtue of work requirements and/or recreational habits, but they also tend to seek medical help later than women, and only when they present some degree of impairment.¹² According to Misch *et al.*,¹³ in many, but not all, ethnic groups, the ratio of affected males to females is 2:1. However, male preponderance is not universal and a more balanced distribution, or even female predominance, has been reported.^{12,14,15}

Table 4. Frequency of psychosocial disabilities, assessed at the time of diagnosis, of leprosy patients ($n = 56$) referred to the Hospital Eduardo de Menezes, Belo Horizonte, MG, Brazil, during the period January 2009 to October 2010

Grade and score (rating scale)	Frequency	%
Social interaction (Participation scale)		
No restriction (score 0)	39	69.8
No significant restriction (score 1–12)	5	10.6
Mild restriction (score 13–22)	5	8.9
Moderate restriction (score 23–32)	5	8.9
Severe to extreme restriction (score 33–90)	1	1.8
Stigma (Jacoby scale)		
Absent (score 0)	38	67.9
Present (score 1–3)	18	32.1
Depression (Hamilton scale)		
No depression (0–6)	23	41.1
Mild (score 7–17)	19	34.0
Moderate (score 18–24)	9	16.0
Severe (score 25–50)	5	8.9

Leprosy is essentially an adult disease by reason of its protracted incubation period.^{11,15} However, our results showed that around 10% of the study population comprised young individuals, a proportion that was high in comparison with the values reported by the Brazilian Ministry of Health² for cases notified in 2013 at both national (7.8% youths) and state (4.1% youths) levels. The emergence of leprosy in young individuals suggests the presence of strong risk factors, such as genetic relatedness, close contact with leprosy patients (especially those with the lepromatous forms of the disease), low educational level, food insecurity, exposure to contaminated water, soil or armadillos, infrequent changing of bed linen, and absence of bacillus Calmette-Guérin (BCG) vaccination.¹³ The incidence of leprosy in 11 to 15-year olds represents an important marker of endemicity and featured prominently in the programme “More Health: a right of all” (*Mais Saude: direito de todos*) launched in 2007 by the Brazilian Ministry of Health with the aim of reducing by 10% the coefficient of detection of new cases of leprosy within this age group by 2011.¹⁶

The predominance of leprosy in darker-skinned individuals is in accordance with the national figure of 67% reported by the Brazilian Ministry of Health for the period 2009–2010,¹⁶ but much lower than the value of 85.8% reported by Côrrea *et al.*¹¹ following an epidemiological study of leprosy patients in São Luis (Maranhão). Darker-skinned individuals make up 43.8% of the Brazilian population, and the predominance of leprosy within this group is likely associated with their lower socio-economical indicators in comparison with white-skinned subjects.¹⁷

Epidemiological studies have shown that a low level or absence of education is associated with the emergence of leprosy, the development of more severe forms of the disease, and non-adherence to MDT. Most experts agree that education changes behavior towards leprosy and other neglected diseases, and that such subjects should be discussed within the school environment.^{18–20} In 2014, the Brazilian Ministry of Health launched a campaign entitled “Leprosy, worms and trachoma are curable. Do this homework and protect yourself” (*Hanseníase, verminoses e tracoma têm cura. Faça essa lição de casa e proteja-se*) in order

to reach out to nine million schoolchildren and to facilitate early diagnosis in 1 227 municipalities in the country.²¹

Most of the inhabitants of Minas Gerais are urban dwellers (85.3%) and the majority of the new leprosy patients originated from the centre of Minas Gerais, an area that encompasses the densely populated metropolitan region of the capital Belo Horizonte and houses approximately 27% of the population of the state.²² Hence, it was not surprising to find that the study population comprised mainly urban residents (94.6%). Following a study involving 165 municipalities in the northeastern state of Ceará, which is highly endemic for leprosy with 1.96 cases per 10 000 inhabitants according to 2013 figures, Kerr-Pontes *et al.*²³ established that the disease was associated with a high level of poverty and with rapid, unplanned and uncontrolled urbanisation.

The finding that most new leprosy patients were married is in accordance with previous reports.^{24–26} The primary source of human leprosy is transmission by other humans, hence household and familial relations (particularly conjugal partners) constitute strong risk factors since close contact can facilitate transfer of the causative agent.²⁷ Although leprosy can exert a detrimental impact on the emotional and sexual aspects of a conjugal relationship, the positive side is that married couples can support each other during the lengthy process of diagnosis and treatment.²⁶

The high percentage of employed individuals amongst the leprosy patients (75%) was probably because the study group comprised only new cases of the disease. Leprosy has important economical consequences since it hampers the ability of the patient to generate income by increasing absenteeism at work and, ultimately, by preventing the sufferer from being gainfully employed.

The clinical types of leprosy depend on specific host immunity and range from tuberculoid, in patients with higher resistance to *M. leprae*, through borderline forms to lepromatous, in patients with the lowest levels of resistance. The vast majority (92.8%) of new patients exhibited borderline or borderline lepromatous forms of the disease indicating that the general level of resistance was low. Furthermore, since an inverse relationship exists between the numbers of lesions and resistance to the bacillus, the high frequency of patients with five lesions or more observed in the present study may be explained by the immunogenetic characteristics of the surveyed population.²⁸

In order to provide patients with an appropriate MDT regimen, leprosy has been classified on the basis of skin smears as PB or MB. However, when the results of bacilloscopy are unreliable or unavailable, clinical criteria are employed in the grouping of patients whereby those with ≤ 5 skin lesions are classified as PB while those with >5 skin lesions are categorized as MB. Unfortunately, this type of operational classification has important limitations, as demonstrated by Cavalcanti *et al.*²⁹ who studied 1213 new cases of leprosy and found that 23% of bacilloscopy-negative patients presented more than five skin lesions while 11% of bacilloscopy-positive patients exhibited five or fewer lesions. From a clinical viewpoint, the type and duration of the therapy regimen depends on the results of clinical manifestations and bacilloscopy in order to ensure the selection of true MB cases that require more intense treatment.

In the present study, around 95% of patients were classified as MB and, since such patients are considered highly contagious, the treatment applied was MDT/MB (rifampicin, clofazimine and dapson), or alternatives, as recommended by the Brazilian Ministry of Health³⁰ even though many of the subjects were bacilloscopy-negative. The predominance of MB patients in the study group was even higher than the values reported in previous

studies,^{12,15} and according to many researchers such a high frequency is an indication of late diagnosis,^{31,32} a situation that contributes to the maintenance of the disease transmission chain. For this reason, it is critical that surveillance is intensified in Brazil in order to ensure that infected individuals are diagnosed during the initial stages of the disease when infection is still in the indeterminate form.

Leprosy is characterised by Type 1 and 2 acute reactional episodes and the unpleasantness of these events often prompts the patient to seek medical help, resulting in diagnosis of the disease. Among the study patients, Type 1 reactions were more frequent than Type 2 (44.7 and 25%, respectively). Type 1 reactions can occur in any leprosy subtype, although they are most prevalent in the borderline forms, and are characterised by sudden episodes of exacerbated hypersensitivity to *M. leprae* in skin and/or nerves. Neuritis (thickening and pain) is the most severe manifestation, and nerve damage can cause disability and deformity. The care and management of Type 1 patients is a major challenge for the health system.³³ In contrast, Type 2 reactions are typically rather infrequent (<5% of leprosy patients) and occur almost exclusively in patients with MB leprosy, especially those classified as borderline lepromatous.³³ The most common manifestation of a Type 2 episode is erythema nodosum, which may be accompanied by systemic symptoms such as fever, malaise, anorexia, lymphadenopathy, orchitis, iritis, iridocyclitis or glomerulonephritis. Leprosy patients experiencing a reactional state undergo a reduction in leisure and social activities and prefer isolation, engendered not only by the distressing pain but also because of constraints generated by physical changes and fear of the reaction of other people in general.³⁴

PHYSICAL AND PSYCHOSOCIAL LIMITATIONS OF NEW LEPROSY PATIENTS

According to the IG rating, nearly 60% of the new leprosy patients exhibited physical disabilities of Grade 1 or 2, and this figure is higher than the 36.1% reported in a study carried out by Chagas *et al.*³⁵ Interestingly, the frequency of Grade 2 disabilities among new leprosy patients (16%) was much greater than the official figure of 10.4% recorded for Minas Gerais in 2013.¹ It is possible that there has been an improvement since the period of our study (2009–2010), but it is more likely that the discrepancy arises from the different sample sizes and/or methods of population selection employed in the two surveys. Another explanation for the difference is that diagnosis can be even further delayed because the process of booking an appointment in referral hospitals is protracted. In the present study, the predominance of Grade 1 and 2 disabilities was associated with MB cases (borderline and borderline lepromatous forms), and indicates delayed diagnosis and hidden prevalence (non-detected cases). Despite the implementation of MDT policies, there is a reservoir of non-detected cases that sustains the sources of infection.³⁶ According to Kalk,³⁷ the methods of estimating hidden prevalence are questionable and the true dimensions of the leprosy problem are likely underestimated.

EHF scores are determined through summation of the IG grades associated with each eye, hand and foot, and range between 0 and 12. In the present study, the mean EHF score determined at the time of diagnosis was 1.55, thereby confirming the high frequency of patients with physical disabilities. However, familiarity with leprosy is essential in order to initiate appropriate therapy and health care workers should not only observe the more obvious signs of leprosy but should be aware of the possible systemic involvement.^{38,39}

The SALSA scale is a reliable interview-based tool comprising 20 questions that can be applied by medical or non-medical workers who have received appropriate training.^{5,40} The

questionnaire was developed to measure activity limitation together with safety awareness encountered by people with leprosy, diabetes and other neuropathies in both developing and developed areas. Since patients with leprosy may experience loss of sensitivity in hands or feet, it is important that they are aware of their limitations and of the necessity of avoiding risky activities that can cause injuries or, at the very least, of modifying how such activities are performed. In this context, the SALSA scale provides an additional safety awareness component, the outcome of which is a score in the range 0 to 11 with the higher scores indicating increasing awareness of the risks of certain activities. According to the SALSA scale, more than one-third of the leprosy patients studied herein exhibited mild limitation, while around 10% presented moderate to severe limitation at the time of diagnosis. Regarding safety awareness, 55.4% of the patients were unaware of any risky activities. Considering that three-quarters of the study group was within the normal working age range of 16 to 60 years, the absence of safety awareness in more than half of the patients is highly relevant and a cause for some concern. In a study carried out in Sobral (Ceará, Brazil) by Barbosa *et al.*¹⁵ involving 69 individuals who had been discharged from MDT, the SALSA safety awareness component revealed that 56.7% had no perception of risk. These investigators stated that the application of the SALSA scale was not difficult, an opinion that the authors of the present paper share. We strongly recommend the use of this questionnaire before, during and after MDT to assess the real status of the patient in order to propose an effective rehabilitation program, which could range from psychological treatment to reconstructive surgery, tailored to the specific needs of the individual.

The GPAS scale was originally designed for use under circumstances that prevail in Nepal, where it has been validated,^{6,41} even though leprosy has not been considered a public health problem in Nepal since 2009.⁴² The GPAS is an interview-based tool developed by van Brakel *et al.*⁶ to assess disease-induced impediments, such as impaired sensitivity, weak muscles or deformities of the hands or feet that make difficult everyday movements and work. The tool comprises 42 questions relating to problems encountered in daily living, difficulties in relationships and the use of aid devices. In the present study, the SALSA and GPAS scales provided similar results with overall frequencies of 46.5 and 48.2% indicated, respectively, for mild to severe activity limitations among the new leprosy patients. To the best of our knowledge, this is the first report regarding the application of the GPAS scale in a Brazilian setting, and for this purpose, our group translated the scale into Portuguese. The scale was easy to apply and could be used, after validation, by trained medical or non-medical workers in basic health units in Brazil.

Participation is defined as personal involvement in life situations (i.e. interpersonal, domestic, social, civil, economic and educational domains), while the problems experienced in participating in such situations are referred to as participation restrictions.^{7,41,43} The Participation questionnaire used in the present study was developed and validated simultaneously in seven languages, including Portuguese, and comprises 18 questions that generate total scores between 0 and 90. According to the Participation scale, the percentage of new leprosy patients that had experienced severe/extreme restriction on social participation was similar to the proportion (1.4%) reported by Barbosa *et al.*¹⁵ in a group of patients who had completed MDT. In the present study, we found that the scale was easy to apply and could be used by trained medical and non-medical workers in basic health units in Brazil.

Although the Jacoby stigma scale was originally designed to evaluate patients with epilepsy, it was used here to measure perceived stigma in new leprosy patients. Stigma is very difficult to measure because it can be experienced as enacted (explicit) or felt (perceived)

exclusion or discrimination. Typically, stigma commences with labeling and stereotyping of a subject with disease-related disabilities, and leads ultimately to separation of the individual from society. Such consequences can have more severe effects on the self-esteem and sense of purpose of the individual than the disease itself.^{41,44,45} The Jacoby questionnaire consists of three subjective questions, the answers to which can be “no” (score 0) or “yes” (score 1) such that the scores vary from 0 to 3.⁸ Application of the questionnaire to new leprosy patients revealed that around one-third had experienced stigma at the time of diagnosis. In a study conducted in Nepal, Brouwers *et al.*⁴¹ found that perceived stigma was significantly higher among people with leprosy-related disabilities (Grades 1 and 2) than in healthy controls.

Although assessment of subjective phenomena has become an important part of health surveillance, in our opinion quantification of perceived stigma is difficult for the following reasons: (i) the interviewer may choose to accept imprecise answers or attempt to extract precise answers from patients, (ii) the interview may simply reinforce artifacts of the interviewing method rather than uncovering real problems, (iii) the severity of the disease and the personality of the individual may influence the responses, (iv) the feeling of stigma may be the result of the patient experiencing the fear that others have in dealing with someone with deformities, and (v) the perception of stigma depends on the socio-cultural environment of the patient and how leprosy is perceived by family, friends and colleagues at work, hence misconceptions and lack of information regarding the disease may influence the answers. Although the interviewers were instructed to read the questions exactly as written and provide feedback to reinforce the patients’ answers, there is no guarantee that the questionnaire reflected exactly the feelings of the study population. Although the scale is easy to apply, we feel unable to propose its application in the case of leprosy patients.

Application of the Hamilton depression scale followed the structured interview guide proposed by Williams⁴⁶ involving 21 questions relating to work, activities, mood, retardation, agitation, anxiety, insomnia, feelings of guilt, hypochondria, loss of weight, depersonalization/derealisation, suicide, and somatic, genital, paranoid, obsessional and compulsive symptoms. The questionnaire was applied by a health professional because it demands considerable input from the interviewer, and scores between 0 and 50 were generated from the answers provided. Of the new leprosy patients assessed in the present study, 8.9% presented severe depression according to the Hamilton scale. Even though implementation of the Hamilton scale is challenging, its application to leprosy patients presenting Grade 1 and 2 disabilities could contribute to the better assessment of the needs of these individuals and the interventions that they require. However, it is worth noting that, although depression-rating scales are used to quantify the presence and severity of symptoms by adopting pre-established objective criteria, there is always an element of subjectivity on the part of the patient and the interviewer in assigning scores.⁴⁷ Since many of the symptoms of psychiatric disorders are inherently subjective, measures of depression should only be considered as rough estimates.

Conclusions

Although the cross-sectional nature of the study precluded the establishment of cause-effect relationships, it was possible to draw definite conclusions regarding the status of the new leprosy patients referred to the Hospital Eduardo de Menezes. Of the study group assessed: (i) a large proportion (60%) exhibited Grade 1 or 2 physical disabilities; (ii) approximately

46% experienced activity limitations and lacked safety awareness, (iii) around 30% presented difficulties in social interaction and perceived leprosy-related stigma, and (iv) some 60% suffered from some degree of depression. Based on our experience, we strongly recommend the systematic use of IG and EHF forms for the evaluation of physical disabilities, whereas the assessment of activity limitations should be conducted using SALSA or, alternatively, GPAS. These tools should be applied at the time of diagnosis, and during and after MDT treatment, thereby allowing an integrated approach for the management of patients with leprosy. However, forms should be shortened (but not oversimplified) and contain only relevant items in order to facilitate assessment.

Regarding leprosy management and control, our recommendations are: (i) considering that the key issue associated with the elimination of leprosy in Brazil is that of delayed diagnosis, campaigns such as that sponsored by the Brazilian Ministry of Health in 2014²¹ should be maintained as a continuing programme (ii) given that three out of every four patients were referred from primary or secondary care services, in which the skills and/or facilities to manage leprosy were unavailable, it is important to reconsider every aspect of the referral process. Referral is not simply transferring a patient from a lower to a higher level of care, and it does not end when a patient is discharged from a referral hospital. A highly effective referral system requires good communication and coordination between primary, secondary and tertiary carers, and support from higher to lower levels. Generally, referral hospitals adopt an inward-looking perspective, focusing exclusively on the patients directly under their care. Referral hospitals should offer support to personnel in lower-level facilities, and specialist staff members should ideally spend more of their time providing advice and support beyond the confines of their hospital, either in person or through electronic means of communication. These problems will need to be addressed with some urgency if Brazil is to achieve the WHO goal of removing leprosy from the list of public health diseases.

Acknowledgements

We are grateful to Dr. Wim van Brakel for providing the rating scales used in this study, to the patients who agreed to participate in the study, and to the staff of Hospital Eduardo de Menezes for valuable help in collecting the data.

Authors' contributions

SHLM, MAFG, MOCR, LFL and SL contributed to the experimental design of the study. SHLM, MAFG, SPS, CAA, EDS, JA and ACG performed all experiments and participated in the acquisition and analysis of data. SHLM, MAFG, SL and MOCR contributed to data interpretation, drafting and final revision of the manuscript. In addition, all authors read and approved the final version of the manuscript.

Further Acknowledgments

This research received funds from the Fundação de Amparo à Pesquisa do Estado de Minas Gerais (FAPEMIG) in the form of scholarships for undergraduate students (SPS and CAA).

Declaration of independence

The funding source was not involved in the design of the study, in the collection, analysis or interpretation of data, in the writing of the report, or in the decision to submit the paper for publication.

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