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Leprosy-related disabilities after release from multidrug treatment: prevalence and spatial distribution

ABSTRACT

OBJECTIVE: To estimate the frequency of people with leprosy-related physical disabilities after release from multidrug treatment and to analyze their spatial distribution.

METHODS: Descriptive cross-sectional study with 232 leprosy patients treated between 1998 and 2006. Physical disabilities were assessed using the World Health Organization disability grading and the eye-hand-foot (EHF) sum score. The residential address of patients and rehabilitation centers were geocoded. It was estimated the overall frequency of physical disability and frequency by disability grade (grade 0, grade 1, and grade 2) according to the WHO disability grading taking into consideration clinical and sociodemographic variables in the descriptive analysis. Student's t-test, chi-square test ($\chi 2$), and Fisher's test were used as appropriate at a 5% significance level.

RESULTS: Of the patients studied, 51.6% were female, mean age 54 years old (SD 15.7), 30.5% had less than 2 years of formal education, 43.5% were employed, and 26.9% were retired. Borderline leprosy was the most prevalent form of leprosy (39.9%). A total of 32% of these patients had disabilities according to the WHO disability grading and the EHF score. Disabilities increased with age ($p = 0.029$), they were more common in patients with multibacillary leprosy ($p = 0.005$) and poor self-rated physical health ($p < 0.001$). Those who required prevention/rehabilitation care traveled on average 5.5 km to the rehabilitation center. People with physical disabilities lived scattered across the city but they were mostly concentrated in the most densely populated and socioeconomically deprived area.

CONCLUSIONS: There is a high frequency of people with leprosy-related disabilities after release from multidrug therapy. Prevention and rehabilitation actions should target uneducated and older patients, those who had multibacillary forms of leprosy and poor self-rated physical health. The travel distance to rehabilitation centers calls for reorganization of local care networks.

DESCRIPTORS: Leprosy, complications. Leprosy, epidemiology. Leprostatic Agents, therapeutic use. Disabled Persons. Occupational Therapy. Cross-Sectional Studies.

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INTRODUCTION

Of the Americas, Brazil is the country with the heaviest responsibility for endemic leprosy (37,610 cases in 2009), and is among the 12 countries which together account for 90% of the cases in the world. Among the three countries with more than one million inhabitants which have not yet eliminated the disease, Brazil, Nepal and East Timor, it is in first place.[22]

Physical disabilities caused by peripheral neurological damage, which may affect individuals before, during and after treatment,[a] are a serious problem.

The WHO Disability Grading System (WHO-DGS), used to measure physical disability has come to be one of the indicators used to evaluate the disease in Brazil.[b] This indicator grades disability due to leprosy, aids professionals in monitoring the patients properly, helps in understanding the chain of infection and allows the evolution of the disease to be tracked.[4]

Adopting such an indicator to evaluate, monitor cases and track the endemic disease does not guarantee the care and rehabilitation needed for those who have the physical disabilities common to leprosy.[4] The situation becomes more delicate after discharge, and is little recognised by the health authorities. Patients continue to develop disabilities resulting from leprosy reactions which may occur up to eight years after finishing treatment.[15]

Patients and professionals equate finishing the treatment with a discharge from the Prevention and Rehabilitation of Disability due to Leprosy service (PRD), which is mistaken.[8] Croft et al[3] showed that in multibacillary cases, which treatment begins with nerve function already altered, there is a risk of up to 65% of presenting new damage during treatment; in paucibacillary leprosy, the risk is 16%.

Guidelines for caring and monitoring the patient post-discharge are recommended.[a] Around 23% of leprosy patients have some degree of disability (grade 1 and 2) after they are discharged.[16] However, the prevalence of grade 2 disability varies from 17% to 50% post-discharge, according to a revision of global data by Deepak (2003).[5]

Evaluation and monitoring to prevent disabilities should be carried out upon diagnosis, during treatment and after finishing the treatment.[a]

The reference centres which are part of the health care system play a fundamental role in helping primary care services deal with complications of the disease, preventing disability and providing rehabilitation from damage caused by leprosy, even post-discharge.[22]

It is only possible to direct campaigns for eliminating and/or controlling leprosy as a public health problem by using different strategies which increase the accessibility to diagnosis, treatment, monitoring and complete rehabilitation for the patients.[20,21]

The aim of this study was to estimate the frequency of disability caused by leprosy after discharge, and to analyse the distance between patients' residences and rehabilitation services.

METHODS

This is a transversal descriptive study of 335 individuals who have had multibacillary or paucibacillary leprosy, of both sexes and without pre-established age limits, who started treatment between 2/1/1998 and 31/12/2006 in the municipality of São José do Rio Preto, SP.

Of the 335 individuals treated, 223 (66.5%) were located and interviewed. We failed to locate 91 people (27.2%) due to change of address, returned correspondence or absence in both of the attempts to visit; 10 (3.0%) refused to participate, 9 (2.7%) had died and 2 (0.6%) denied having had the disease.

The municipality's demographic and social indicators are comparable to those of developed countries. The municipality has a Human Development Index of 0.834, considered to be high by the UN Development Programme.[c]

In order for their data to form part of this body of analysis, patients had to have finished their treatment and been discharged at the time the protocols were applied. Those who had moved to other municipalities were excluded.

Cases eligible for this study were identified in the Hansen project database,[14] created after detailed investigation of data in the Sistema de Informação Nacional de Agravos e Notificação (SINAN – National Information System for Diseases Notification), of the Epidemiological Monitoring of Municipal Health Secretariat of São José do Rio Preto, SP, spreadsheets on leprosy and the Dermatology Outpatient Clinic of the Hospital de Base da Faculdade de Medicina de São José do Rio Preto (FAMERP) spreadsheets. The data were

[a] Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância Epidemiológica. Manual de prevenção de incapacidades. 3ª ed. Brasília; 2008.
[b] Secretaria de Comunicação Social da Presidência da República. OMS adota indicadores do Brasil para controlar hanseníase. Brasília (DF); 2009 [cited 2009 Aug 12]. Available from: http://portal.saude.gov.br/portal/aplicacoes/noticias/default.cfm?pg=dspDetalheNoticia&id_area=124&CO_NOTICIA=10441
[c] Secretaria Municipal de Planejamento e Gestão Estratégica. Conjuntura Econômica 2010. 25ª ed. São José do Rio Preto; 2010.

compared and synthesised into one spreadsheet and checked against information from the medical records of individuals treated in the municipality between 1998 and 2006.

Those who have or had leprosy in the municipality are treated in two reference services: Núcleo de Gestão Assistencial-60 (NGA-60) and the Dermatology Outpatient Clinic of the Hospital de Base da Faculdade de Medicina de São José do Rio Preto. The reference services provide services for the prevention and rehabilitation of disabilities in leprosy.

In these two centres, the patients undergo a complete evaluation during their consultations or, at the very least, every three months during the treatment and are given advice on techniques for preventing disabilities. This advice is given verbally, sometimes with the aid of teaching material and patients and their families are given demonstrations of how these should be carried out and their understanding is confirmed during the occupational therapy (OT) sessions. The patients are advised to attend the OT department in the Prevention and Rehabilitation of Disability due to Leprosy service for every complication they experience after being discharged and, if none are experienced, every six months in the year after discharge and once a year for five years after discharge.

The participants were contacted by telephone (up to three attempts), by letter (up to three sent) or home visit (up to two attempts). Information on general and clinical data was sought and a simplified neurological evaluation (SNE) to assess the WHO Grade of Disability WHO-GDS and of Eye Hand and Foot (EHF).[a,b,c]

There were 20 questions about general and clinical data, partly taken from the WHO CIF© checklist from September 2001, and they encompassed information on the individual's health conditions and personal information.

The SNE enabled us to evaluate disabilities in the eyes, the nose, hands and feet and synthesise them to estimate the grade of disability according to the WHO system which grades between 0, 1 and 2 and the EHF score, 15% more sensitive than the WHO-DGS.[6] in order to obtain the EHF score, the grade of disability assigned to the eyes, hands and feet are added, using the same criteria as the WHO-DGS. There is a minimum score of zero (no incapacities) and a maximum of 12.

The results are shown as percentages or mean and standard deviation. We carried out an analysis of the variables, considering disability and socio-demographic indicators, clinical history and time elapsed since onset of the disease.

We used the computer application SPSS version 15.0, SPSS Inc., Chicago, IL and EPI-INFO 2002 (version 3.4.1) for the statistical analysis. We presented total frequencies and for the grade 0, grade 1 and grade 2 groups, considering clinical and socio-demographic variables in the descriptive analysis.

Disability grades 1 and 2 were grouped together for purposes of analysing the correlation between the presence of disability and the independent variables, as the group with severe disabilities (grade 2) was small. We used the Student's T-test, Chi-squared (χ^2) or Fisher test, as appropriate, taking $p \leq 0.05$ as significant.

The residential addresses of the former patients and of the rehabilitation services for present and former leprosy sufferers in the municipality were geocoded using metric interpolation. This was carried out using tools from the Mapinfo programme (MapInfo Professional Version 7.0. MapInfo Corporation) and the Cartographic Base of São José do Rio Preto (in UTM - Universal Transverse Mercator) using streets as axes. A thematic map was produced with the location of the rehabilitation services and individuals according to the grade of disability.

The maximum, minimum and average distances (with standard deviation) in a straight line between the individuals' residences and the location of the above-mentioned rehabilitation services in São José do Rio

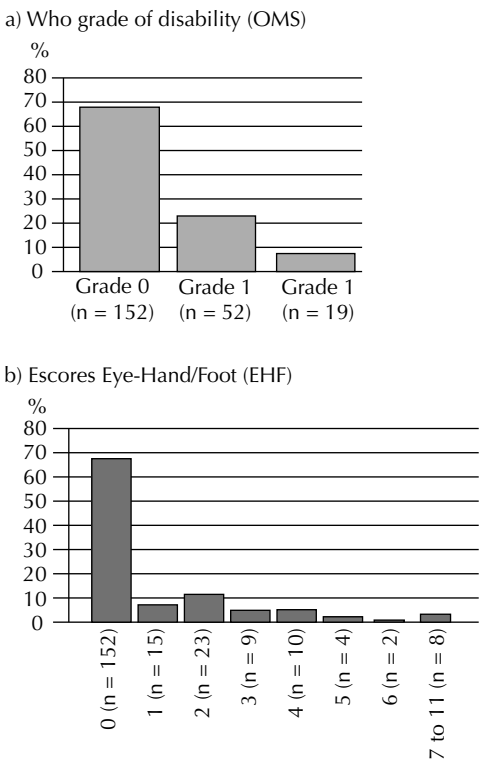

Figure1. Percentage distribution of WHO grade of disability (a) and of *Eyes-Hand and Feet(EHF)* indicator (b) for 232 former leprosy patients evaluated after discharge. São José do Rio Preto, SP, Southeastern Brazil, 1998 to 2006.

Preto, which deal with around 80% of leprosy cases in the municipality, were calculated for each disability garden (WHO-DGS 0, 1 and 2) of the individuals using the ArcGIS 9.1 programme.

RESULTS

Of the 223 interviewed individuals, 51.6% were female, with an average age of 54.0 (sd 15.7), 61.8% had not completed elementary education, 43.5% worked, 26.9% were retired and 29.6% did not work.

The predominant form of the disease among the former patients was borderline leprosy, affecting 39.9%, followed by the lepromatous (23.8%), tuberculoid (21.1%) and undetermined forms (15.2%). 50.2% and 59.2% respectively considered their physical and mental health to be good in the month previous to the interview. From the former patients, 54.7% reported feeling pain, with the most common being in the spine (31.4%) and the knee (17,0%).

Grades 1 and 2 and EHF > 0, even after discharge, were found in 32.0% of cases, and 8.6% had serious disabilities (Figure 1).

The average age of the former patients with disabilities (WHO-DGS 1 and 2) (57.5 years old: sd 14.1) was higher than that of those without (grade 0) (52.3 years old; sd 16.2), p = 0.029. The other socio-demographic variables were not linked with the presence of disabilities, although p was close to the level of significance (p = 0.051) in the case of having disabilities and not having gone to school, or having gone for less than two years (Table 1).

Some degree of disability was more frequent in those who had had the borderline and lepromatous forms of the disease, compared to those who had paucibacillary leprosy (undetermined and tuberculoid: p = 0.005) and those former patients who judged their own health to be very bad in the month previous to the interview (p < 0.001) (Table 2).

Although disabilities were more frequent in those former patients who evaluated their mental health as very bad in the month previous to the interview, there was no statistical difference regarding those who had an associated disease and those who had been hospitalised at least once in the previous year when compared with those who did not have any disabilities.

The most common associated diseases were diabetes (10.3) and high blood pressure (29.1%). We also verified the presence of depression, gastric, cardiac and rheumatic problems, epilepsy, labyrinthitis and osteoporosis.

We analysed the frequency of disability at different periods after discharge: up to three years after, between

Table 1. Frequency of socio-demographic characteristics of leprosy patients according to WHO grade of disability. São José do Rio Preto, SP, Southeastern Brazil, 1998 to 2006.

Socio-demographic characteristics	n	n = 151 Grade 0		n = 52 Grade 1		n = 19 Grade 2	
		n	%	n	%	n	%
Sex							
Female	115	83	72.2	23	20.0	9	7.8
Male	107	68	63.6	29	27.1	10	9.3
Age (years)[a]							
12 to 34[a]	30	24	80	5	16.7	1	5.3
35 to 54	78	56	71.8	16	20.5	6	7.7
55 or over	114	71	62.3	31	27.2	12	10.5
Formal education (years)[c]							
< 2	68	41	60.3	20	29.4	7	10.3
2 to 7,9	91	63	69.2	23	25.3	5	5.5
≥ 8	58	45	77.6	7	12.1	6	10.3
Marital status							
With partner	143	98	68.5	33	23.1	12	8.4
No partner	79	53	67.1	19	24.1	7	8.9
Household income (minimum wage)[b,c]							
≤ 3	124	80	64.5	31	25	13	10.5
> 3	94	69	73.4	20	21.3	5	5.3

[a] Three patients were aged < than 15 years old (one was 12 and two were 13)
[b] Minimum wage at the time: R$ 350.00 (U$ 160.5)
[c] Total numbers (n) differ due to "missing" values

Table 2. Distribution of frequency and correlation between clinical/personal history and grade of disability of patients with leprosy according to the WHO. São José do Rio Preto, SP, Southeastern Brazil, 1998 to 2006.

Clinical/personal history	n	n = 151 Grade 0		n = 52 Grade 1		n = 19 Grade 2	
		n	%	n	%	n	%
Form of the disease							
Indeterminate	34	32	94.1	2	5.9	0	0.0
Tuberculoid	47	32	68.1	8	17.0	7	14.9
Borderline	89	60	67.4	22	24.7	7	7.9
Lepromatous	52	27	51.9	20	38.5	5	9.6
Opinion of physical health in the previous month							
Good	111	91	82	13	11.7	7	6.3
Moderate	73	40	54.8	27	37.0	6	8.2
Very bad	38	20	52.6	12	31.6	6	15.8
Opinion of mental health in the previous month							
Good	131	95	72.5	27	20.6	9	6.9
Moderate	65	41	63.1	17	26.2	7	10.8
Very bad	26	15	57.7	8	30.8	3	11.5
Associated diseases							
No	101	72	71.3	22	21.8	7	6.9
Yes	121	79	65.3	30	24.8	12	9.9
Hospitalisation in the previous year							
No	186	130	69.9	43	23.1	13	7
Yes	36	21	58.3	9	25	6	16.7
Alcohol consumption							
No	184	123	66.8	44	23.9	17	9.2
Yes	38	28	73.7	8	21.1	2	5.3

Table 3. Mean, minimum and maximum distances in kilometres between rehabilitation services (Núcleo de Reabilitação Municipal) and the residences of the former leprosy patients. São José do Rio Preto, SP, Southeastern Brazil, 1998 to 2006.

Situation	Number	Mean distance	Standard deviation	Minimum distance	Maximum distance
DGS-WHO = 0	147	5.3	1.7	1.0	8.6
DGS-WHO = 1 or 2	70	5.5	1.5	2.3	8.3
Total[a]	217	5.4	1.7	1.0	8.6

[a] Exact locations of six former patients could not be identified in the SIG MapInfo7 programme.

three and six years after and six to nine years after. We found no differences in the frequency of disability in these periods (p = 0.3862).

The municipality's rehabilitation services which dealt with users fromm Brazilian Unified Health System (SUS), including leprosy cases, were far from those former patients who needed care, be that primary prevention (grade 0) or secondary prevention (grades 1 and 2). The locations of the rehabilitation services were restricted to the south east region of the city, and almost all of the patients lived in other areas (Figure 2). The exact addresses of six patients could not be identified in the SIG MapInfo7 programme, as they lived in a region distant from the urbanised zone.

The average distance travelled by the users was 5.4Km, measured from the Municipal Rehabilitation Centre, in which 80% of the total appointments in prevention and rehabilitation took place (Table 3). The former patients who needed prevention/rehabilitation for some kind of disability (grade 1 or 2) had to cover an average distance, in a straight line, of 5.5 km to access the service.

DISCUSSION

Knowing the frequency of disabilities caused by leprosy can help define action strategies for their prevention. The frequency found in this study was high and was

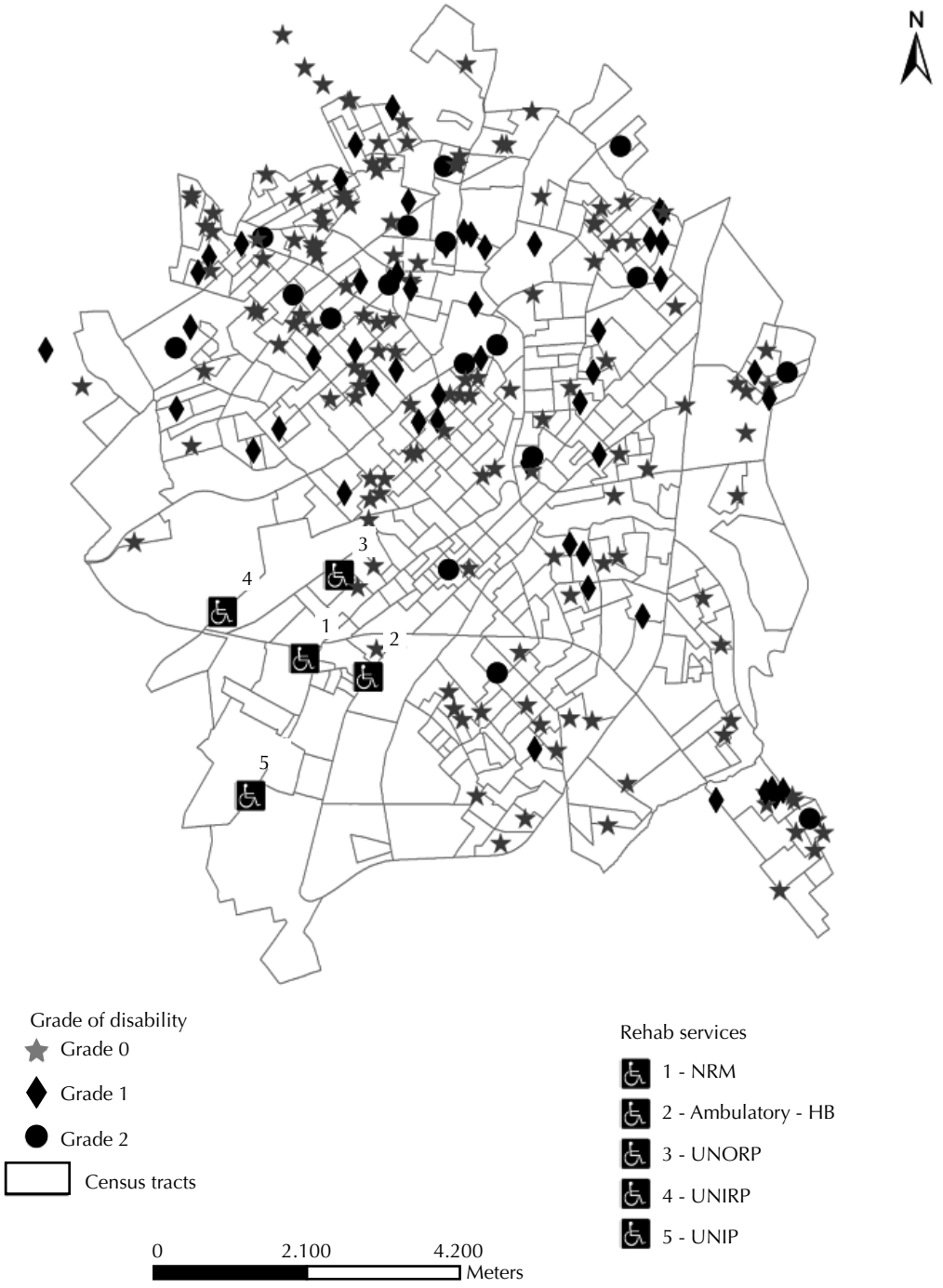

Figure 2. Spatial distribution of rehabilitation services and residences of ex-patients with leprosy, according to WHO grade of disability. São José do Rio Preto, SP, Southeastern Brazil, 1998 to 2006.

similar to the results of Meima et al[11] (2001) and Ramos & Souto[16] (2010).

In the period in which this study was carried out, 359 patients had been or were being treated in São José do Rio Preto; 85.7% did not have any grade of disability upon diagnosis.[2] However, 62.0% of the former patients we evaluated showed a higher percentage of disability after being discharged (32.0%) than they had at the time of diagnosis, which leads us to believe that reactions occurring after discharge may contribute to the onset of disabilities.

The greater incidence of disabilities in multibacillary cases observed in this study and in that of Ramos &

Souto[16] (2010), which evaluated former patients for up to four years after being discharged, has also been found in studies evaluating disabilities during treatment.[5,13,17] Moschioni et al[13] (2010) showed that patients with the multibacillary form had a 5.7 greater chance of having disabilities compared to paucibacillary cases. This may be due to multibacillary cases being diagnosed later, which may favour the onset of disability, which is closely linked with time.[21]

Disabilities and limitations in activities grow worse and become more frequent with age, irrespective of leprosy.[12,13,18] Professionals need to be aware of this fact and plan health care for this population bearing in mind the probable future need for further care.

Previous studies found links between disabilities at time of diagnosis and low level of education.[12,13] Although not significant ($p = 0.051$), the results of this study suggest a higher level of education may contribute to the prevention of disabilities, an association which can be verified with an increase in the number of cases analysed. Those with more time in the educational system, in addition to possibly having easier access to the health care system, may pay more attention to changes to their body, which may lead them to seek help earlier.[9,19]

The patients' opinions of their own health is strongly associated with the presence of disabilities. The former patients report not having the same ability carrying out certain tasks as they had before the onset of disability. Difficulty in carrying out day-to-day tasks which require preserved neural function leads the patients themselves to evaluate their health as impaired.[10]

Access to rehabilitation services still functions in a one-way direction, i.e., patient-service, which does not favour accessibility to those most in need. Individuals with disabilities need treatment centres close to where they live if the care and guidance of the professionals is to be effective.

The distribution of those who have finished their treatment for leprosy and who have disabilities (grade 1 and 2) is greater in the north of São José do Rio Preto, an area with greater population density and with more socio-economically deprived neighbourhoods.[c]

The reference centre which dealt with almost 80% of the leprosy cases is close to the other rehabilitation services. However, these services are distant from the areas with the greatest concentrations of patients. This may contribute to the former patients not having evaluations, routine guidance and early intervention after discharge, a period in which reactions and neuritis, which are factors in triggering disabilities,[2] can easily occur, even though advised to.

In spite of the municipality of São José do Rio Preto providing excellent care for leprosy patients, there is a gap in linking the service which provides the medical care and that which provides prevention and rehabilitation of physical disabilities. Patients who need prevention/rehabilitation services, even after being discharged, need to travel an average, straight line, distance of 5.5 km (sd 1.7), for which some form of transport (bus, car or motorbike) is necessary, making the treatment more onerous. If the calculations were made with the actual routes taken by the former patients, the values would be even higher than those we obtained.

Accessibility for those with special needs is widely discussed as a guarantee of the health system's principle of equality. All individuals in Brazilian society, among them those suffering from the consequence of leprosy, should have the same opportunities for health care. It is urgent that effective measures be taken to develop public policy which acts to reduce the inequalities in accessibility that exist between citizens.[1]

A limitation of this study was that only two thirds of the former patients treated during the period of the study were evaluated. This loss was mainly due to changes of address or inability to locate individuals. 3% refused to take part in the study. We can assume that the loss was not due to incidence of disability. In the study carried out by Ramos & Souto,[16] around 80% of the patients were located, but 25% were evaluated for disabilities, which corresponds to outpatients treated between 2004 and 2008.

The design of the study did not allow us to evaluate the evolution or the incidence of disabilities after discharge. However, disability evaluation was carried out on all of the former patients who were discharged in the period of the study, it was not restricted to those who continued being treated as an outpatient. This enabled us to better estimate the frequency of disability post-discharge. The former patients had a high frequency of disability, which suggests the necessity of on-going care after finishing their medical treatment. The health service should adopt measures to ensure adequate follow-up of these individuals after discharge, such as scheduling check-ups for up to five years after discharge and updating former patients address details.

The prevention and rehabilitation of physical disabilities due to leprosy continues to be a challenge in reducing the impact of this disease. The results of this study suggest that older former patients, those who had the multibacillary form of the disease and those with low levels of education need special attention in order to prevent and rehabilitate disabilities. The health service should be located somewhere easily accessible for patients who need care and one option for increasing accessibility would be the de-centralisation of rehabilitation services. Investment and campaigns

in improving the quality of life of those affected by leprosy should be incentivised both during and after treatment through means of techniques which prevent disability and rehabilitation based in the community.[2,10,20]

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