

Clinical-Epidemiological Profile of Patients Living with Leprosy

ORIGINAL

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Abstract

Background: Leprosy is an infectious disease that is manifested in dermatological signs and symptoms and can interfere with activities of daily living.

Objective: To describe the clinical and epidemiological profile of leprosy patients.

Methods: A cross-sectional study was conducted with 41 patients diagnosed with leprosy, treated between 2011 and 2013. The SALSA Scale (Screening of Activity Limitation and Safety Awareness) was applied to check the limitations in activities of daily living and data were analysed quantitatively and statistically.

Result: The patients were aged between 23 and 59 years, mostly male, with a high prevalence of tuberculoid leprosy, without co-morbidities and outpatient discharge. The SALSA Scale score was relevant for individuals without limitations in domains such as mobility, self-care, work and dexterity.

Conclusion: Patients have few limitations for carrying out their daily activities, as well as a low disability level.

Introduction

Leprosy is an infectious disease with dermatological signs and symptoms of slow evolution, caused by *Mycobacterium leprae*, an intracellular parasite with tropism for skin cells and peripheral nerves [1].

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Keywords

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As this is a highly infectious disease with low pathogenicity, many individuals are infected but few develop the disease. It affects people of all ages, and of both sexes, however its incidence is higher in men than in women. Among the forms of disease transmission are direct and prolonged contact with a multibacillary contagious patient and untreated skin or mucous membranes of the upper airways [1].

Brazil accounts for 94% of leprosy cases in the Americas [2]. The transmission of leprosy is linked to socio-economic factors such as nutritional status, hygiene and living conditions; however, genetic factors are also linked with individuals' predisposition to acquire leprosy [3].

Thus, the risk of leprosy in Brazil is related to major social inequalities and the disease remains significant as a public health problem. Research in 2014 regarding leprosy distribution in the world found that the total number of detected new cases (180,618) was lower than in 2013 (215,656), except in the African region. More than 50% of cases are reported in areas where 17.5% of the population lives. Issues related to migration between endemic and non-endemic areas, poor housing conditions and sanitation and the level of social development are factors that affect the high endemicity of leprosy [4].

According to clinical and operational classification, leprosy can be classified into paucibacillary (up to five skin lesions) and multibacillary (more than five skin lesions). Among the paucibacillary forms are indeterminate leprosy and tuberculoid leprosy, and among the multibacillary forms are borderline leprosy and lepromatous leprosy [5].

Criteria for classifying the physical disability of leprosy patients are established by the Ministry of Health: Level 0 (zero): no disability, there is no neural impairment in the eyes, hands and feet; Level I (one): presence of disability, i.e. there is a decrease or loss in sensibility in the eyes, hands and/or feet; Level II (two): presence of disabilities and deformities in the eyes (lagophthalmos, ectropion and/or

trichiasis), hands and feet with claw and/or bone resorption [6].

Currently, multidrug therapy (MDT) is performed as a treatment and it has the function of breaking the epidemiological chain of the disease. As well as drug therapy, monitoring is carried out by the rehabilitation team to prevent deformities due to peripheral nerve injuries caused by the disease [1].

The multidrug leprosy treatment has no effect on the nerve fibres already damaged, hence the importance of health education and disability prevention [7].

The causative mechanisms of deformities and disabilities are neurogenic and inflammatory. Among the neurogenic causes considered primary are: sensory, motor and autonomic deficits; and secondary: retractions, trauma and post-traumatic infections [6].

Serious injury can occur in facial peripheral nerves (auricular, trigeminal and facial), upper-limb nerves (ulnar, median and radial) and lower-limb nerves (fibular and tibial). Among the injuries, there are sensory disturbances (hyperesthesia and anaesthesia) and motor disturbances (paralysis and amyotrophy), plus minor deformities such as callosities, ulcerations, bone resorption, loss of body hair, keratitis and conjunctivitis, among others [6, 7].

According to the International Classification of Functioning (ICF) [8], disability is defined as a generic term for deficiencies, activity limitations and participation restrictions. The ICF considers both the activities performed by an individual, such as their functions and social participation, indicating negative aspects of the interaction of an individual who has a health condition, and contextual factors, divided between environmental and personal factors.

Based on ICF, the SALSA Scale was developed to verify the limitation of activities performed as well as their risk and the awareness of risk by patients [6].

The high level of incapacity of leprosy has been the main problem associated with the disease, be-

cause it interferes directly in the patient's work and daily activities, causing economic losses, as well as psychological trauma because of stigma and discrimination [9].

The prevention of disabilities is a priority of the leprosy control programme, and it is present in all stages of treatment, including follow-up post-discharge [10].

In Brazil, health centres for the care of leprosy patients realize the prevention of disabilities, in order to provide the patient with maintenance or improvement of their physical, socio-economic and emotional state. Thus, the objective is to describe the clinical and epidemiological profile of patients with leprosy.

Methods

This is a cross-sectional, exploratory and descriptive study, with convenience sampling and a quantitative approach.

Seventy patients from the leprosy ambulatory of the Dermatology Centre of the Faculdade de Medicina do ABC (FMABC) were contacted and, from these, 41 patients were chosen to participate in the research protocol.

The FMABC has insured outpatient clinics under the Unified Health System (SUS) and covers seven municipalities in the region: Santo André, São Bernardo do Campo, São Caetano do Sul, Diadema, Mauá, Ribeirão Pires and Rio Grande da Serra. The leprosy clinic's main function is to follow-up of patients of patients through diagnostic scanning, treatment and follow-up post-discharge, even after a cure.

Inclusion criteria were: having leprosy or having undergone treatment for leprosy, regardless of the type and classification; being older than 18, both sexes; voluntary participation in the study and being aware of the Statement of Consent. Exclusion criteria were: inconclusive diagnosis of leprosy; associated cognitive deficits and associated diseases,

such as rheumatic, neurological and/or traumatology-orthopaedic.

For data collection, records of Simplified Neurological Assessment recommended by the Ministry of Health [6] were used. Data on vision (self-reported as "difficult" or "without difficulty"), muscle strength (through the muscle strength test and characterized as preserved or decreased) and sensitivity (conducted with a Semmes-Weinstein aesthesiometer kit, consisting of six monofilaments of the Sorri Brazil brand) were collected.

Afterwards, the SALSA Scale (Screening of Activity Limitation and Safety Awareness) was applied. The scale consists of 20 questions, which may be administered in about 10 minutes, and evaluates the limitations of daily activities divided into categories of mobility, dexterity, self-care and work, as well as the awareness of risk of people with leprosy or other peripheral neuropathies [6, 11].

The SALSA Scale scores are distributed as follows: 0 to 24 –without limitation; 25 to 39 –mild limitation; 40 to 49 –moderate limitation; 50 to 59 –severe limitation; 60 to 80 –very severe limitation [11]. For a risk awareness score, which ranges from 0 to 11 points, the evaluator should add up the points relating to "I physically cannot" and "I avoid because of the risk". Thus, values closer to 11 points indicate greater awareness of the risks involved in certain activities [6, 11].

Data were analysed quantitatively, using Epi Info version 6.0. Non-parametric statistical data were analysed by ANOVA (Analysis of Variance) and Kruskal-Wallis tests for mean differences between SALSA and Risk Awareness scores with the study variables age and vision. p values < 0.05 were considered statistically significant.

Results

Information on the sex, working conditions and health of the participants are presented in **Table 1**.

Table 1. Distribution of sex, working conditions and health of leprosy patients seen at the ambulatory of the FMABC, Santo André, São Paulo, Brazil, 2012-2013.

Variable	N	%
Sex		
Male	26	63.4
Female	15	36.6
Working condition		
Retired	7	17.1
Away/Unemployed	2	4.8
Housewife	6	14.6
Formal/Informal Work	26	63.4
Types of leprosy		
IL	7	17.1
TL	18	43.9
BTL	1	2.4
BLL	10	24.4
LL	5	12.2
Leprosy classification		
PB	25	61
MB	16	39
Secondary diagnosis		
DM	3	7.3
HPN	2	4.9
DM and HPN	1	2.4
Denies diseases	35	85.4
Current condition of the disease		
Ambulatory discharge	24	58.5
Treatment	17	41.5
Total	41	100
IL: indeterminate leprosy; TL: tuberculoid leprosy; BTL: borderline-tuberculoid leprosy; BLL: borderline-lepromatous leprosy; LL: lepromatous leprosy; PB: paucibacillary; MB: multibacillary; DM: diabetes mellitus; HPN: hypertension.		

The highest prevalence of ages found in the study was between 23 and 59 years, of which 26 patients were male and 15 female.

With regard to working status, 63.4% performed some sort of paid activity, indicating that a large number of patients were active and productive socially.

Table 2. Use of adaptations, vision, muscular strength and sensibility conditions and disability level in patients with leprosy seen at the ambulatory of the FMABC, Santo André, Sao Paulo, Brazil, 2012-2013.

Variable	N	%
Use of adaptation		
Yes	12	29.3
No	29	70.7
Orthose		
Yes	2	4.9
No	39	95.1
Glasses		
Yes	10	24.4
No	31	75.6
Vision		
With difficulty	5	12.2
Without difficulty	36	87.8
Muscle strength		
Preserved	33	80.5
Low	8	19.5
Sensibility		
Preserved	34	82.9
Low/Moderate	5	12.2
Severe	2	4.9
Disability level		
0 (Zero)	35	85.4
I (One)	1	2.4
II (Two)	5	12.2
Total	41	100
Disability level 0 – no disability; level I – presence of disability; level 2 – disability and deformity.		

When they were asked about co-morbidities, 32 patients denied any kind of disease.

There was a prevalence of tuberculoid leprosy (TL – 43.9%), followed by borderline-lepromatous leprosy (BLL – 24.4%), of which 58.5% were in ambulatorial discharge and 41.5% in treatment with multidrug therapy.

Data in **Table 2** indicate the use of adaptations, types of assistive technologies and degrees of disability. Most patients (70.7%) did not use any type of adaptation, 10 patients wore glasses and two wore orthoses during rest and/or for upper-limb positioning.

Most patients reported no problems with vision or loss of muscle strength, and only two patients showed severe loss of tactile sensitivity during sensory evaluation.

With regard to the degree of disability, 35 patients (85.4%) had level 0 and only five patients (12.2%) had level II.

Table 3 shows the levels of limitation in activities according to the SALSA Scale: mobility, self-care, work and dexterity. On this scale, 24 patients had no limitations in daily living activities and only five showed moderate, severe or very severe limitations.

The Risk Awareness score ranged from zero to 11 points. Zero points were found in 26 interviews and 11 points in only one interview.

Table 4 shows the statistically significant results of mean differences between SALSA score and Risk Awareness, compared to the variables: age and vision.

The analyses of quantitative variables were presented as mean, minimum/maximum values and standard deviation. To compare mean values bet-

Table 3. Limitation level distribution according to the SALSA Scale score of patients with leprosy seen at the ambulatory of the FMABC, Santo André, Sao Paulo, Brazil, 2012-2013

Variable	N	%
SALSA limitation level		
No limitation	24	58.5
Mild limitation	12	29.3
Moderate limitation	1	2.4
Severe limitation	3	7.3
Very severe limitation	1	2.4
Total	41	100

SALSA Scale: Activity Limitation and Risk Awareness Screening.

Table 4. Mean differences between SALSA score and Risk Awareness with the statistically significant study variables (age and vision), conducted in patients with leprosy seen at the ambulatory of the FMABC, Santo André, Sao Paulo, Brazil, 2012-2013.

Variable		N	Mean	Min/Max	DP	p	Scores
SALSA Score							
Age	23–59	22	48.09	23/72	15.629	0.018*	1
	60–96	19	60.26	36/96	15.979		2
Risk Awareness Score							
Age	23–59	27	0.63	0/6	1.597	0.027**	3
	60–96	14	1.929	0/11	3.075		1
SALSA Scale Categories							
Visão	Preserved	36	0.806	0/11	2.081	0.041*	2
	Decreased	5	3	0/6	2.828		3

* ANOVA, ** Kruskal-Wallis

ween SALSA and age, an ANOVA test was performed, where $p = 0.018$ and $p = 0.041$ were obtained for Vision and Risk Awareness Score, respectively. Likewise, to compare data to age and Risk Awareness, there were statistically significant p -values ($p = 0.027$) in the Kruskal-Wallis test.

Discussion

This study aimed to describe the clinical-epidemiological profile of leprosy patients from the ambulatory of leprosy of the FMABC.

The analysis of the categorization of leprosy patients showed a higher frequency of male patients. Studies with leprosy patients also found more male patients [12, 13].

The frequency according to age varies according to the region analysed; however, in Brazil, the highest incidence is in adults [14]. The prevalence in age here was between 23 and 59 years (66%), followed by between 60 and 96 years old (34%).

Among the activities mentioned by the participants, seven were retired, six were housewives, 26 were employed, and two were unemployed and/or laid off. Thus, 63.4% had some type of paid activity, indicating that a large amount of patients are active and socially productive. In a survey of 69 leprosy patients in Ceará, Brazil, 79.8% had some occupation [15]. On the other hand, the study reports on the negative impact of leprosy in terms of the socio-economic aspects of people affected by this disease, who most often are laid off and/or retired [16]. It can thus be inferred that because of easy access to treatment and multiprofessional work, many patients remain working using their labouring and everyday skills.

When asked about co-morbidities, most denied any kind of associated disease; however, some reported hypertension and diabetes mellitus (**Table 1**). Similarly, in a study with 26 patients, 15 denied associated diseases and the others reported changes

in cholesterol levels, hypertension, diabetes mellitus and/or other diseases [17].

Serious injury may occur in the peripheral nerves of leprosy patients, including sensory and motor disturbances and deformities [18]. However, in our study, lesions were not observed in peripheral nerves, as supported by data on the use of adaptation and disability level (**Table 2**).

With regard to the SALSA Scale, the most frequent score was 24 points, showing that the majority of patients have no limitations in daily life activities. Likewise, a search more frequently obtained a SALSA score of 32 points [12]. However, respondents here are in various stages of Risk Awareness, showing the need to make them aware. It was found that the greater the vision problem, the worse the score in Risk Awareness, and the higher the age, the worse the score on the SALSA Scale (**Table 4**).

In a study of 282 patients, the Risk Awareness score varied from 0 to 7 points, demonstrating the low risk perception of participants [19]. Similar results indicate that the patient has difficulty in understanding the meaning of the word "risk" when carrying out certain daily living activities and other measures should be taken to help the patient to understand the importance of discussion and risks [12].

Thus, the use of the SALSA Scale is one of the Brazilian Ministry of Health recommendations aimed at physical prevention and analysing activities with functional limitations, aiding in the rehabilitation of leprosy patients, since many patients are diagnosed late [6, 20].

Rehabilitation and disability prevention strategies over the years have been very important, and currently professionals are aware that rehabilitation is an element of treatment and care of patients with leprosy [21].

The *Guide to Leprosy Control*, developed by the Brazilian Ministry of Health, states that treatment is the key to cure, and it is the strategy for the control and eradication of leprosy in the country. During multidrug therapy treatment, actions such

as prevention of disabilities and deformities and rehabilitation, when necessary, should be carried out to the full [1].

Disability prevention techniques, when accepted and carried out by patients daily, contribute to minimizing or avoiding the worsening of deformities. Such techniques involve health education, skin hydration, exercises and use of assistive technology [22]. Non-pharmacological interventions, neural monitoring, health education, exercise guidance and prescription orthotics in services are associated with the evolution of the degree of disability of patients [23].

After leprosy diagnosis, health education of the patient and family is needed, with the aim of answering their questions and uniting the family in the assistance, treatment and rehabilitation of the patient [22].

In addition to physical disabilities, stigma has a major impact on the physical well-being, as well as the psychological, economic and social participation, of these subjects, making it a public health, social and rehabilitation issue [24].

The need to develop and implement effective strategies to control leprosy is directly related to poor health-related quality of life, even in the cured patient, since it affects lower social classes, affecting the subject's work and quality of life [25].

Besides of the high disabling potential, leprosy is associated with non-compliance to treatment, due to political, socioeconomic and cultural factors and lifestyle habits [26].

The Health care is defined by results of complex interactions involving the diagnosis, treatment, and prevention of diseases [27]. In this way, health professionals should integrate public health practices to promote the health of the population [26, 27].

The partnership between healthcare services and the patient is considered as the gold standard for a successful result in disease healing. Patients in vulnerable condition, usually suffer from social exclusion. Thus, the three dimensions of vulnerability

(individual, social and programmatic) must be considered by the managers of public health [28].

To reduce the patient's vulnerability, there is the need of public health planning that involves diseases control e health promotion [29, 30].

The limitation of this study was due to some research deviation as patient's migration, untraceable or another health problem. At the beginning of this survey there were seventy patients that were supposed to participate, but unfortunately only 41 answered the SALSA Scale.

Conclusion

The clinical and epidemiological profile of patients with leprosy showing as a serious service public health problem even today. The prevalence is between 23 and 59 years old, of which 63.4% have some professional occupation. The most frequent type of leprosy is tuberculoid, with an incapacity level suggestive of the absence of deformities and difficulties in daily life activities.

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