PHYSICAL DISABILITIES IN LEPROSY: CHARACTERIZATION, FACTORS RELATED AND EVOLUTION*

Gabriela de Cássia Ribeiro[1], Francisco Carlos Félix Lana[2]

[1]Nurse. Ph.D. in Nursing. Nursing professor at the Federal University of Vale do Jequitinhonha e Mucuri. Diamantina, Minas Gerais, Brazil.
[2]Nurse. Ph.D. in Nursing. Professor at the Nursing School of the Federal University of Minas Gerais. Belo Horizonte, Minas Gerais, Brazil.

ABSTRACT: The aim of this study was tocharacterize the new cases of leprosy; analyze socioeconomic, demographic, clinical-epidemiological, and access to diagnosis and treatment aspects related to the occurrence of leprosy with physical disabilities; and analyze the development of disabilities during treatment.A retrospective cohort survey was conducted in the health region of Diamantina, Minas Gerais, Brazil. One hundred seven reports of leprosy and 71 interviews were analyzed between 2005 and 2010. The most frequent diagnoses were multibacillary (73.2%) and physical disability (79.1%). There was a statistical relationship between the development of physical deformities and those affected by leprosy with lower levels of schooling, higher neural involvement, and greater difficulties in accessing the health unit, in addition to the maintenance of the degree of disability. There is a reduced operational capacity of the Family Health Strategy (FHS) regarding leprosy control actions and the need to implement the policy according to the Unified Health System (SUS, from its acronym in Portuguese).
DESCRIPTORS: Leprosy; Epidemiology; Disabled persons; Health services accessibility.

INCAPACIDADES FÍSICAS EM HANSENÍASE: CARACTERIZAÇÃO, FATORES RELACIONADOS E EVOLUÇÃO

RESUMO: Este estudo objetivou caracterizar os casos novos de hanseníase; analisar os aspectos socioeconômicos, demográficos, clínico-epidemiológicos e de acesso ao diagnóstico e tratamento relacionados à ocorrência de hanseníase com incapacidades físicas; e a evolução das incapacidades durante o tratamento. Foi realizada uma pesquisa de coorte retrospectiva na região de saúde de Diamantina-MG. Foram analisadas 107 notificações de hanseníase entre 2005 a 2010 e 71 entrevistas. A maioria dos diagnósticos foram multibacilares (73,2%) e com incapacidade física (79,1%). Houve relação estatística entre o desenvolvimento de deformidades físicas e os acometidos pela hanseníase com menor nível de escolaridade, com maior comprometimento neural e com maior dificuldade de deslocamento até a unidade de saúde, além de manutenção do grau de incapacidade física. Existe uma reduzida capacidade operacional da Estratégia de Saúde da Família quanto às Ações de Controle da Hanseníase e necessidade de implementação da política de acordo com o Sistema Único de Saúde.
DESCRITORES: Hanseníase; Epidemiologia; Pessoas com incapacidade física; Acesso aos serviços de saúde.

INCAPACIDADES FÍSICAS EN ENFERMEDAD DE HANSEN: CARACTERIZACIÓN, FACTORES ASOCIADOS Y EVOLUCIÓN

RESUMEN: Este estudio tuvo el objetivo de caracterizar los casos nuevos de enfermedad de Hansen; analizar los aspectos socioeconómicos, demográficos, clínico-epidemiológicos y de acceso al diagnóstico y tratamiento relacionados a la ocurrencia de enfermedad de Hansen con incapacidades físicas; y la evolución de las incapacidades durante el tratamiento. Fue realizada una investigación retrospectiva en la región de salud de Diamantina-MG. Fueron analizadas 107 notificaciones de enfermedad de Hansen entre 2005 y 2010, así como 71 entrevistas. La mayoría de los diagnósticos fue de multibacilares (73,2%) y con incapacidad física (79,1%). Hubo relación estadística entre el desarrollo de deformidades físicas y los acometidos por la enfermedad de Hansen con menor nivel de escolaridad, con mayor comprometimiento neural y con mayor dificultad de desplazamiento hasta la unidad de salud, además de manutención del grado de incapacidad física. Hay una reducida capacidad operacional de la Estrategia de Salud de la Familia cuanto a las Acciones de Control de Enfermedad de Hansen y necesidad de implementación de la política de acuerdo con el Sistema Único de Salud.
DESCRIPTORES: Enfermedad de Hansen; Epidemiología; Personas con incapacidad física; Acceso a los servicios de salud.

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Corresponding author:
Gabriela de Cássia Ribeiro
Universidade Federal dos Vales do Jequitinhonha e Mucuri
Rodovia MGT 367, Km 583, nº 5000 - 39100-000 - Diamantina, MG, Brasil
E-mail: gabriela.ribeiro@ufvjm.edu.br

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INTRODUCTION

Leprosy has great importance for public health because it is an infectious and chronic disease that primarily affects people in poor socioeconomic conditions. It has a long incubation period and there is a predilection for a bacillus known as mycobacterium leprae by neural and epithelial cells, which makes it a highly disabling disease[1].

However, leprosy is curable with supervised treatment using multidrug therapy (MDT), which may be of 6 or 12 months' duration, depending on the operational classification[2].

Leprosy patients are classified according to the number of skin lesions, bacterial load, and level of involvement of the peripheral nerves.When there is no neural involvement, patients are classified as grade 0 in terms of disability. Grade 1 disability occurs when there is a decrease or loss of sensitivity in the eyes, hands, and feet, and grade 2 disability when there are more serious injuries inthe eyes, hands, and feet[2].

These complications may be responsible for permanent damage, as they may reach the nerve receptors responsible for pain, vision and tactile sensitivity, making the individuals affected by it more susceptible to accidents, burns, wounds, and even amputations, resulting in social and psychological damage that affects their quality of life[3].

For this reason, in 2010 the World Health Organization published The Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011-2015), and outlined the overall objective for the year 2015: a reduction of 35% in leprosy diagnosis withgrade 2 disability per 100,000 inhabitants, compared to the data presented in 2010[1,4].

For the success and scope of the proposed goal, the early diagnosis of leprosy is necessary, followed by proper treatment, surveillance of contacts, and access to public health services[5].

In 2013, Brazil recorded 31,044 new cases, presenting a detection rate of 15.44/100,000 inhabitants; 64.4% of these new cases were diagnosed as multibacillary, and 7.3% of patients had grade 2disability[6].

In 201, the health region of Diamantina, Minas Gerais, Brazil, presented 16 new cases of leprosy, a detection rate of 9.6/100,000 inhabitants. However, 56.3% of the reports corresponded to the diagnosis of grade 2 disability[7].

With the large number of late diagnoses and grade 2 disability in the health region of Diamantina, the objectives of this study were to characterize the new leprosy cases in the region in the period between 2005 to 2010 andanalyze the socioeconomic, demographic, clinical-epidemiological, and access to diagnosis and treatment aspects related to the occurrence of leprosy with physical disabilities, in addition to identifying the development of disabilities in the diagnosis and in the discharge medication.

METHOD

An epidemiological with retrospective cohort study was conductedagainst the backdrop of the health region of Diamantina, located in Vale do Jequitinhonha, Minas Gerais, Brazil. The region has 15 municipalities and approximately 167,000 inhabitants.

The period defined for the study included the years from 2005 to 2010. The choice of this time periodwas made due to a specific feature of the physical disabilities related to leprosy, which are highly sensitive to fluctuations in the operational capacity of health services, especially regarding staff turnover.

In five of the municipalities, there was no diagnosis of leprosy in this period. The research was conducted in 10 cities that had made notifications, which were: Alvorada de Minas; Carbonita; Coluna; Couto de Magalhães de Minas; Datas; Diamantina; Gouveia; Itamarandiba; Presidente Kubitschek; and Serro.

The database of the Information System for Notifiable Diseases (SINAN, from its acronym in Portuguese) "Leprosy for analysis of notifications" was made available by the Coordination of the Sanitary Dermatology Programfrom the State Department of Health and Health Regional Superintendence of Diamantina.

To collect data, a structured questionnaire, divided into blocks, was used. The first block included the analysis of the SINAN notifications of new cases of leprosy, and the other blocks were related to socioeconomic, demographic, clinical-epidemiological, and access to diagnosis and treatment aspects.

One hundred seven SINAN reporting forms were evaluated, and the sample consisted of 71 respondents. Thirty-six did not participate in the study due to moving to cities outside the study area (10), impossibility of locating the individual

(15), and death (11).

Data collection took place between February and March 2011. The subjects were contacted by the professionals of the Family Health Strategy (FHS) to which they belonged, and the interviews were conducted in their homes or their health facilities. For the interviews, the estimated duration was approximately 25 minutes, and did not show refusal.

As the dependent variable, the degree of physical disability in the diagnosis was chosen. The independent variables were: socioeconomic and demographic characteristics (gender, age, years of schooling, family income, and integration into the labor market); clinical-epidemiological aspects (operational classification, clinical form, detection mode, number of damaged nerves, and number of skin lesions); access to diagnosis and treatment (demand for health services after the first symptoms, services that performed the diagnosis and treatment, time to perform the diagnosis and initiate treatment, number of health professionals needed for the diagnosis, and difficulty of accessing the health unit); and the evolution of disability (relation of the degree of incapacity in the diagnosis and in the discharge).

A database was created using statistical software Epi Info, version 6.0. After checking for inconsistencies, data were exported to Microsoft Excel 2010, and then to the statistical program SPSS, version 18.0.

A bivariate descriptive analysis was conducted. The tests included the Chi-square test and Fisher's exact for categorical variables and Kruskal-Wallis for numerical variables. To evaluate the correlation between the degree of physical disability in the diagnosis and at discharge, the marginal homogeneity test was used. It was found that they all had as statistical reference the value of $p<0.05$.

The research proposal was submitted to the ethics committee of the Federal University of Minas Gerais, and approved with opinion number ETIC 0512.0.203.000-10 in November 2010. All participants were advised about the research objectives and, after authorization, signed an informed consent form. Therefore, participants were assured the guarantee of anonymity and confidentiality of information.

RESULTS

One hundred seven notifications of new cases of leprosy were analyzed, and the city of Diamantina had the highest proportion of cases, with 47.7% (n=51), followed by the municipalities of Presidente Kubitschek, Serro, and Coluna, with 11.2% (n=12), 10.3% (n=11), and 9.3% (n=10), respectively. The new case detection rate found in the study period was 12.3/100,000 inhabitants.

To analyze the factors that relate to the presence of diagnoses with physical disabilities, the information from the 71 interviews with individuals from the health region of Diamantinawas used.

Table 1 shows the relationship between the clinical-epidemiological aspects at the time of leprosy diagnosis and the presence of physical disabilities.

Table 1 – Relationship between clinical-epidemiological aspects and physical disabilities. Health region of Diamantina, Minas Gerais, Brazil, 2005-2010

	Degree of physical disability at the time of diagnosis			
	Grade 0	Grade 1	Grade 2	p
	N (%)	N (%)	N (%)	
Clinical form				
Undeter-mined	4 (26.7)	9 (60)	2 (13.3)	
Tuberculoid	2 (66.7)	-	1 (33.3)	0.050**
Dimorphic	4 (10.5)	19 (50)	15 (39.5)	
Virchowian	4 (36.4)	5 (45.4)	2 (18.2)	
Operational classification				
PB	6 (31.6)	11 (57.9)	2 (10.5)	0.107*
MB	9 (17.3)	25 (48.1)	18 (34.6)	
Detection mode				
Passive	12 (21.8)	30 (54.5)	13 (23.6)	0.498**
Active	1 (11.2)	4 (44.4)	4 (44.4)	

PB – Paucibacillary; MB – Multibacillary; *Chi-square test; **Fisher's test

It was possible to identify a large number of diagnoses made in the multibacillary forms of leprosy (73.2%). Of these, the dimorphic clinical form was the most frequent, followed by Virchowian, corresponding respectively to 73.1% and 21.2%. Following this trend, 79.1% of cases had some type of physical disability at diagnosis, drawing attention to those who had grade 2 disability, which was 29.9%.

The passive form of detection was the most frequent; 77.5% of cases were identified by forwardings and spontaneous demands.

There was a statistically significant relationship between the median of damaged nerves at diagnosis and grade 2 disability (p=0.006), as shown in Table 2.

Table 2 - Relationship between median of damaged nerves, skin lesions, examined contacts and physical disabilities. Health region of Diamantina, Minas Gerais, Brazil, 2005-2010

	Degree of physical disability at the time of diagnosis			
	Grade 0	Grade 1	Grade 2	P*
	Median (Min.-Max.)	Median (Min.-Max.)	Median (Min.-Max.)	
Number of damaged nerves	0 (0-4.5)	2 (1-4)	4 (2.5-7.5)	0.006
Number of skin lesions	4 (1-7)	5 (2-6)	6 (4-6)	0.552
Number of examined contacts	3 (1.7-6.5)	3 (1-4.5)	2 (1-5)	0.739

*Kruskal-Wallis test; Min. – Minimum; Max. – Maximum

In addition to this finding, there was a high median of skin lesions (6) and a low median of examined contacts (2) for those who presented with grade 2 disability.

Table 3 shows the relationship between the level of schooling of those affected by leprosy and the development of physical deformities (p=0.032), because everyone who presented with grade 2 disability had less schooling.

Young people and adults (57.5%), those inserted into the labor market (56.3%), and with family income lower than one minimum wage (52.2%) were mostly affected by grade 1 disability.

The representation of females (52.1%) was slightly larger than males, which was 47.9%. However, men obtained a higher number of grade 2 diagnoses of disability (32.4%).

Respondents who reported difficulties getting to health facilities (Table 4) due to physical condition were predominantly diagnosed with grade 2 disability, demonstrating statistical significance (p=0.031).

Only 56 notifications contained information on the evaluation of the degree of disability at discharge (Table 5).

The analysis of the development of disabilities demonstrates a value very close to statistical

Table 3 - Relationship between socioeconomic and demographic characteristics and physical disabilities. Health region of Diamantina, Minas Gerais, Brazil, 2005-2010

	Degree of physical disability at the time of diagnosis			
	Grade 0	Grade 1	Grade 2	p
	N (%)	N (%)	N (%)	
Schooling				
None/ incomplete basic education	11(18.6)	28 (47.5)	20 (33.9)	0.032**
Complete basic education or more	4 (33.3)	8 (66.7)	-	
Age				
18 to 59 years	8 (20)	23 (57.5)	9 (22.5)	0.380*
60 years or more	7 (22.6)	13 (41.9)	11 (35.5)	
Gender				
Female	7 (18.9)	21 (56.8)	9 (24.3)	0.565*
Male	8 (23.5)	15 (44.1)	11 (32.4)	
Integration into the labor market				
Yes	6 (18.7)	18 (56.3)	8 (25)	0.699*
No	9 (23.1)	18 (46.2)	12 (30.7)	
Family income				
≤ 1 minimum wage	4 (17.4)	12 (52.2)	7 (30.4)	0.860*
1 to 3 minimum wages	11 (23)	24 (50)	13 (27)	

* Chi-square test; ** Fisher's test

significance (p=0.050). There is a tendency for the degree of disability between diagnosis and medical discharge to be maintained.

DISCUSSION

The detection rate of new cases of leprosy presented by the municipalities in the study is considered high, according to the parameters of the Ministry of Health[2]. Although this region is considered endemic for leprosy, there are municipalities that for many consecutive years do not perform diagnoses.

Knowledge about the spatial distribution of leprosy and its epidemiological behavior is essential to scale up health surveillance and identify priorities in order to control the endemic

Table 4 - Relationship between access to diagnosis and treatment and physical disabilities. Health region of Diamantina, Minas Gerais, Brazil, 2005-2010

	Degree of physical disability at the time of diagnosis			p*
	Grade 0	Grade 1	Grade 2	
	N (%)	N (%)	N (%)	
Difficulties accessing the health unit				
Yes	7 (21.2)	12 (36.4)	14 (42.4)	0,031
No	8 (21.1)	24 (63.2)	6 (15.7)	
Place where the diagnosis took place				
FHS/CHW	7 (15.6)	25 (55.6)	13 (28.9)	0,301
Others	8 (30.8)	11 (42.3)	7 (26.9)	
Place where treatment was conducted				
FHS/CHW	9 (18.4)	26 (53.1)	14 (28.5)	0.686
Others	6 (27.3)	10 (45.4)	6 (27.3)	
Time lapse between demand and first appointment				
1 to 4 days	9 (20)	25 (55.6)	11 (24.4)	0.535
5 or more days	6 (23.1)	11 (42.3)	9 (34.6)	
Number of consultationsto diagnose				
1 to 3	11 (20.4)	28 (51.9)	15 (27.8)	0.936
4 or more	4 (23.5)	8 (47.1)	5 (29.4)	
Time to diagnose				
Immediate -ly to 6 months	13 (21.1)	31 (50.1)	17 (27.8)	1.000**
6 months to over a year	2 (20)	5 (50)	3 (30)	
Time lapse between diagnosis and the beginning of treatment				
Immediate to 30 days	11 (24.4)	21 (46.7)	13 (27.9)	0.375**
More than 30 days	1 (7.1)	9 (64.3)	4 (28.6)	
Number of health professionals who attended until diagnosis				
1	2 (11.8)	10 (58.8)	5 (29.4)	0.623**
2 or more	13 (24.1)	26 (48.1)	15 (27.8)	

FHS/CHWFamily Health Strategy and Community Health Workers
*Chi-square test; **Fisher's test

disease[8].

High percentages of reported leprosy cases with grade 2 disability and the predominance of multibacillary forms have also been found in studies conducted in another endemic region of Vale do Jequitinhonha, which reinforces the assertion of the persistence of the disease cycle in the region and, consequently, the hidden prevalence[9].

Table 5 – Evolution of the degrees of disability between diagnosis and discharge. Health region of Diamantina, Minas Gerais, Brazil, 2005-2010

	Physical disability at discharge			
	Grade 0 (%)	Grade 1 (%)	Grade 2 (%)	p*
Disability at diagnosis				
Grade 0	7 (53.8)	6 (46.2)	-	0.050
Grade 1	12 (41.4)	14 (48.3)	3 (10.3)	
Grade 2	2 (14.3)	4 (28.6)	8 (57.1)	

*Marginal Homogeneity Test.

Another factor contributing to the inappropriatediagnosis of leprosy is the predominance of passive forms of detection. The current health care model practiced by the primary health care (PHC) services gives priority to serving the individual, neglecting collective and group actions[5], contrary to what the National Primary Care Policy advocates[10].

It is still necessary to progress, because the active search for leprosy cases is an important tool for early diagnosis and reduction of possible complications of the disease[2,11], especially in areas of higher population density, where there is the need to extend the active search to the household and social contacts of the leprosy index case[11].

The results related to the presence of physical disability among those with the highest number of affected nerves meets the findings of a study conducted in the state of Bengal, in India[12]. Adermato-neurological examination of the patient is the basic premise at diagnosis and throughout treatment, as there is greater concern among health professionals with skin lesions presented by the leprosy carrier, leaving behind the neurological component of the disease and especially those classified as pure neural[12].

In this study, men showed a greater number of leprosy diagnosis with complications than women, featuring a later detection. This fact can be explained by the great attention given by women to body aesthetics and by the predominance of programs for women's health[13]. In this sense, the access of men to the PHC service is limited to the treatment of morbidity[14].

There was a significant relationship between a lower level of schooling and grade 2 disability. Low schooling is a strong predictor of poor conditions in terms of housing, nutrition, hygiene, and access to health services[15], determining factors for the

maintenance of the leprosy transmission chain.

Regardless of the level of schooling, it is through health education that people will be sensitized about the first signs of leprosy, the need for early diagnosis, and prevention of disabilities. The various community spaces, such as group meetings, waiting rooms, and television and radio advertisements,can be used to disseminate this information[16].

The expansion of listening spaces for people with leprosy, especially in the PHC, constitutes a challenge to cope with the disease, as health professionals tend to develop actions for the illness and its treatment to the detriment of preventive actions. These spaces need to be truly meaningful for the leprosy carriers, their families, and the community, so that their questions can be answered and their experiences can be shared[17].

The socioeconomic characteristics of the population in the study comprise the social vulnerability framework presented. Considering that the majority of respondents were young people and adults with low family income, it can be inferred that they were inserted in the labor market in heavy manual occupations which, when exposed to the crippling power of leprosy, lead to a future inactive population. Those who manage to stay in the labor market need to adapt to new functions compatible with their health condition, often being subjected to a reduction in monthly income[18,3].

Concomitant to this, these people may become more vulnerable to the appearance of lesions in peripheral areas, especially the feet[12], that compromise their displacement, as demonstrated in this study. Patients with chronic disease develop mobility problems and become dependent on a means of transport to bring them to the health unit, and they usually need to pay for it[19]. This situation can determine the abandonment of treatment, permanence of the stigma generated by the disease, and reduced quality of life.

The FHS stood out as the gateway to the fulfillment of treatment, revealing a movement, although rudimentary, towards the decentralization of leprosy control actions (LCA). Such prevention actions and disease control are inserted into the PHC activities and are even recommended to be incorporated into other public health policies in order to reduce the damage caused by the disease's complications[2,20].

The decentralization of the LCA does not exclude care for leprosy patients in levels of greater complexity, depending on their medical condition and cases of recurrence[21]. However, due to the disorganization of the work process focused on care for leprosy patients in the LCA, it is observed that many units only carry out diagnosis and refer patients for treatment in reference units[22]. Such flow is also observed among municipalities[21]. This is a frequent fact at the Regional Polyclinic of Diamantina which, in addition to other duties, serves as a reference center for leprosy.

Other evidence suggests the late detection of leprosy, as some patients reported that they were diagnosed after seven months of subsequent consultations and the majority had to be assisted by two or more health professionals to complete the case. Although this study did not demonstrate statistical significance for these variables, it is known that these events are sufficient for the evolution of the symptoms and the appearance of physical impairments.

The negligence of information on the evaluation of the degree of disability at discharge was evident. This situation reveals that the services prioritize the assessment of diagnosis and detailthis data during treatment, precluding an accurate analysis of the progression of the degree of disability[9]. The lack of information on leprosy notification compromises the epidemiological surveillance activities[21], and calls the quality of careinto question.

Thus, the analysis of the development of disabilities reveals a tendency to maintain the degree of disability at diagnosis and at discharge, corroborating with findings in other municipalities in Vale do Jequitinhonha (Minas Gerais, Brazil)[9] and in the state of Tocantins (Brazil)[22].

In this sense, it is mandatory that disability prevention actions, such as frequent dermato-neurological examinations, occur in parallel with the disease control measures[13]. Therefore, managers and health professionals need to understand leprosy as a chronic health condition[22] so that the LCA are effective and available throughout the process of diagnosis and treatment, and after discharge.

CONCLUSION

This study had the limitation of a reduced sample size and the impossibility of analysis of some information due to completion failures in the SINAN reporting forms.

However, the study achieved its goals, because the analysis of the results reveals the low schooling level of respondents, the presence of damaged nerves at diagnosis, and the difficulty of accessing the health facility because of physical limitations as factors related to the occurrence of diagnoses with grade 2 disability in the health region of Diamantina. In addition, it was found that there are no actions to reduce the degree of disability between the period of diagnosis and discharge with medication.

The FHS, gateway for leprosy patients, also presents a reduced operating capacity with respect to the LCA. Managers need to plan leprosy actions in the municipalities in accordance with the current public policy, and implement the principles of the Unified Health System (SUS).

It is also necessary to emphasize the need for expansion in the research field of leprosy in this region, in order to understand the epidemiological behavior of the disease and reduce late diagnosis with the presence of physical disabilities.

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