

Deficiencies and disabilities in leprosy: from the diagnosis to discharge by cure

Emanuelle Malzac Freire de Santana¹,
Karen Krystine Gonçalves de Brito²,
Jordana de Almeida Nogueira³,
Oriana Deyze Correia Paiva Leadebal⁴,
Marta Miriam Lopes Costa⁵,
Mirian Alves da Silva⁶,
Maria Júlia Guimarães Oliveira Soares⁷

ABSTRACT

The aim was to compare the level of physical disability of the affected body sites, the deficiencies and disabilities present in affected nerves in the diagnosis and discharge of leprosy patients. This is a study developed between 2009 and 2014 in a reference center for leprosy in Paraíba. It involved 414 medical records, using a structured form. The data were analyzed using descriptive (absolute frequency and percentage) and inferential (Wilcoxon's and McNemar's tests) statistical techniques. There was a decrease of impairment in body sites (nose $p=0.000$), in disabilities (dryness $p=0.002$ and wound $p=0.000$ on the nose and ulcer $p=0.004$ in the feet) and, of the number of affected nerves ($p=0.000$) between the diagnosis and discharge by cure. In the analysis of the years 2009-2014, a reduction of patients presenting level 2 of physical disability was noted. Therefore, in conclusion, even after the discharge, the patients are favorable to develop or to aggravate physical disabilities, needing periodical accompaniment.

Descriptors: Leprosy; Disabled Persons; /prevention & control; Secondary Care.

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¹ Physiotherapist, Master of Nursing. Student of the Graduate Nursing Program, Doctoral level, of the Federal University of Paraíba. Supervisor Professor at the Faculty Maurício de Nassau – João Pessoa. João Pessoa, PB, Brazil. E-mail: manumalzac@gmail.com.

² Nurse, Master of Nursing. Student of the Nursing Graduate Program, Doctoral level, at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: karen_enf@yahoo.com.br.

³ Nurse, Ph.D. in Nursing. Associate Professor at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: jalnogueira31@gmail.com.

⁴ Nurse, Ph.D. in Nursing. Adjunct Professor at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: orianadcpl@gmail.com.

⁵ Nurse, Ph.D. in Sociology. Associate Professor at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: marthamiryam@hotmail.com.

⁶ Nurse, Ph.D. in Nursing. Adjunct Professor at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: miads.enf@gmail.com.

⁷ Nurse, Ph.D. in Sociology. Associate Professor at the Federal University of Paraíba. João Pessoa, PB, Brazil. E-mail: mmjulieg@gmail.com.

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INTRODUCTION

Leprosy is an infectious disease of high disability power that has different forms of clinical presentation. The restrict relationship between the Mycobacterium Leprae and the cellular immune response of the host are determinant in the severity of the disease, although its predilection for skin cells and peripheral nerves are scientifically proven⁽¹⁾.

Basically, the causing mechanisms of deficiencies and disabilities in leprosy can occur from the neurogenic and inflammatory pathways. Sensitive, motor and autonomic deficits are classified as primary causes, while traumatic lesions, retractions, and post-traumatic infections are considered secondary, considering their occurrence in the absence of preventive care after the primary process⁽²⁾.

In the first stages, there is an impairment of the thermic sensitivity, followed by the reduction and even loss of the pain and tactile sensitivity. The neural damage is present in more advanced phases, and it can cause paresthesias and muscle paralysis⁽¹⁾. These impairments can make individuals prone to accidents, burns, wounds, and amputations, being responsible for the appearance of permanent sequels⁽³⁾.

Usually, the beginning occurs in an insidious way and without symptoms and, in many cases, can explain the delay in its diagnosis⁽¹⁾, considered a risk factor for the development of disabilities. The late diagnosis and the lack of adequate leprosy treatment can result in a decrease of work capacity, restriction of social participation and, psychological damages⁽⁴⁾.

The deficiencies are described as loss or abnormality of a structure of psychological, physiological or anatomical function, while disabilities are considered consequences of the deficiencies, related to the functional performance to perform an activity. The environmental and social contexts where the individual is inserted determine deficiencies, considering the different cultural perceptions, attitudes, availability of services and legislation⁽⁵⁾.

Data from the World Health Organization show that approximately 14,000 new cases of the disease were diagnosed with a level of disability 2 (LD2) in the global scenario in 2015. Of those, 1,752 were registered only in Brazil, responsible for approximately 89% of all cases with LD2 in the Americas⁽⁶⁾. At the state level, a study of the epidemiological analysis of leprosy in Paraíba verified that at the diagnosis moment, 3.92% of cases already presented LD2⁽⁷⁾.

Considering the physiopathological aspects of the disease and in consonance with the epidemiology cited above, it is indispensable to assess the integrity of the neural function and to classify the level of physical disability (LPD) among the individuals with leprosy at diagnosis as well as in the discharge by cure. This monitoring should be conducted to avoid or minimize the progression of the neural damage, besides preventing possible sequels.

In Brazil, studies involving the physical disabilities of patients with leprosy are in the majority, descriptive or punctual, not involving temporal, evolutive or comparative analyses⁽⁸⁻⁹⁾. Considering this lack of data, studies of prevalence, typology, and tendency of deficiencies and disabilities for monitoring the disease magnitude and the promotion of strategies for injury prevention are pertinent.

Based on the assumption that approximately 20% of all new cases of patients with leprosy present some level of physical disability at the diagnosis and that about 23% will develop disabilities even after being

discharged^(3,10), there was a need to compare the clinical situation of patients in relation to physical disabilities at the diagnosis and at discharge by cure.

In this perspective, this study aimed to compare the level of physical disability, the main affected body sites, the present deficiencies and disabilities and, the nerves affected at diagnosis and discharge by cure.

METHODS

This is a descriptive and retrospective study, population-based and of documental source with a quantitative design. It was conducted between 2009 and 2014 with medical records of patients with a leprosy diagnosis attended in a reference center specialized in the treatment of the disease in the State of Paraíba/PB.

The study population was composed of 485 medical records of patients from the metropolitan region of João Pessoa. The instituted inclusion criteria were: medical records of patients who started and finished leprosy treatment in the reference center and that had filled the simplified assessment of neural functions and complications at diagnosis and at discharge by cure. It was established as exclusion criteria: medical records of patients with cognitive impairment (n=4); records with incomplete information in the simplified assessment of neural functions and complications and, LPD determination (n=61); and records of patients who were not treated during the preconized time by the Health Ministry (HM) (n=6). Therefore, the study sample was composed of 414 medical records.

The data were collected using a structured instrument based on the medical records of patients, from where sociodemographic variables were extracted (sex, age, and education level) and clinical epidemiological (operational classification – paucibacillary or multibacillary, clinical forms – indeterminate, tuberculoid, pure neural, dimorphic and virchowianian).

The instrument was also composed of information referring to diagnosis and discharge by cure available in the simplified assessment of the neural functions and complications. The HM preconizes the use of this assessment, and it is based on a simplified neurological assessment to identify the severity of present lesions in the eyes, nose, hands, and feet⁽¹¹⁾, being a part of the assessment conducted in the service.

In each record, it was considered the maximum level of physical disabilities varying from zero (0) up to two (2). The zero graduation is used when there is no damage in the eyes, hands, and feet, and the level one (1) corresponds to a decrease or loss of sensitivity and the level two (2) when there is the presence of visible deformities due to leprosy⁽¹²⁾. The HM preconizes that the LPD should be assessed at diagnosis, in the occurrence of reactional states and at discharge by cure⁽¹¹⁾.

It stands out that in 2016 a technical-operational manual was released and it was entitled “Guidelines for vigilance, attention, and elimination of leprosy as a public health issue” where the assessment criteria for LPD were modified and started to include the muscle strength as criteria for its determination⁽¹¹⁾. However, as the study refers to the years from 2009 to 2014, this change was not considered.

The data obtained were codified to enter into the application Microsoft Excel and after, exported and analyzed using the software Statistical Package for the Social Sciences (SPSS) version 20. Descriptive statistical techniques were conducted to obtain the absolute frequency and percentage and, inferential statistics using the

Wilcoxon's and McNemar's tests, used to compare the differences between two related samples, being the first used for ordinal variables and the second for nominal variables. The significance level adopted was 5% ($p < 0.05$).

In the investigation process, the ethical observances contemplated in the guidelines and regulating norms for research involving human beings were adopted – Resolution 466/12 of the National Health Council, especially in what refers to secrecy and the data confidentiality. The Ethical Committee in Research of the Center of Health Sciences of the Federal University of Paraíba approved the study project under the protocol 443/14, CAAE 34284414.3.0000.5188.

RESULTS

In the social-demographic and clinical characterization of the population, 243 (59%) were men, 115 (27.8%) were in the age group of 31 to 45 years, 222 (53.6%) completed middle school (53.6%) and, 229 (55.3%) were from the city of João Pessoa. Regarding the clinical characteristics, 251 (61%) were classified as multibacillary, and 145 (35%) had the dimorphic clinical form.

When comparing the LPD at the diagnostic moment and at discharge by cure, there was no significant statistical difference ($p = 0.148$), however, there was an improvement of this indicator, considering the increase of patients classified as level 0 (+3.2%) and reduction of individuals with level 1 (-2.9%) (Table 1).

Table 1: Comparison of the LPD at diagnosis and discharge by cure among patients with leprosy living in the metropolitan region of João Pessoa between 2009 and 2014 (n=414). João Pessoa, PB, Brazil, 2016.

LPD	Diagnosis n (%)	Discharge n (%)	p-value ^(a)
0	246 (59.4)	259 (62.6)	p=0148
1	122 (29.5)	110 (26.6)	
2	46 (11.1)	45 (10.9)	

Footnote: ^(a) Wilcoxon 's test.

In Figure 1, it is possible to observe that the temporal evolution of the LPD between 2009 and 2014. Both at diagnosis and at discharge, there was a dramatic change in the LPD between the years 2009 and 2010 with a considerable increase of LPD 0 and the decrease of LPDs 1 and 2. In the subsequent years, there were oscillations and maintenance of levels with emphasis to reduce the LPD 2 in the year 2014. Also, between 2011 and 2013 there was an increase in the LPD 1.

Regarding the body sites, there was a decrease in its commitment when comparing them at diagnosis and discharge by cure with a statistically significant difference for the nose only ($p = 0.000$) (Table 2).

Table 3 lists the main deficiencies found, showing a reduction in the majority of these in the comparison of the diagnosis and discharge by cure with a statistically significant difference for dryness ($p = 0.002$) and wound ($p = 0.000$) in the nose and, ulcer ($p = 0.004$) in the feet. There was also an increase in deficiencies considered more severe in the hands (rigid grip and reabsorption) and feet (rigid grip, reabsorption, and loose foot), although without statistical relevance.

Figure 1: Temporal evolution of LPD at diagnosis and discharge by cure of patients with leprosy living in the metropolitan region of João Pessoa between 2009 and 2014.

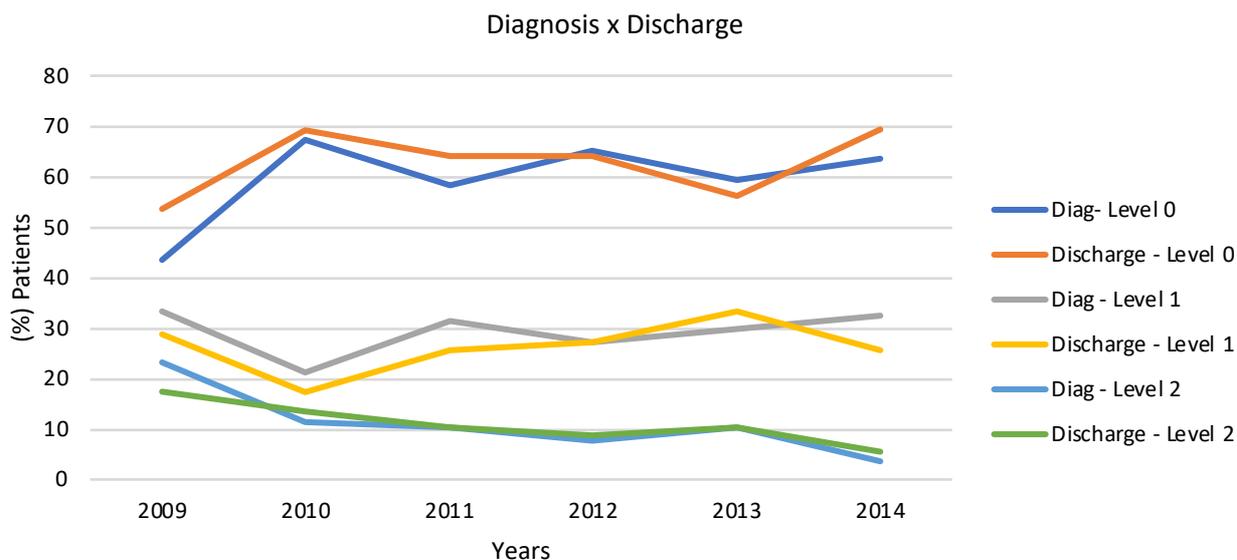


Table 2: Comparison of body sites affected at diagnosis and discharge by cure among patients with leprosy resident in the metropolitan region of João Pessoa between 2000 and 2014 (n=414). João Pessoa, PB, Brazil, 2016.

Affected body site	Diagnosis	Discharge	p-value ^(b)
Eyes	28	19	p=0.137
Nose	47	18	p=0.000*
Hands	58	52	p=0.429
Feet	154	143	p=0.178

Footnote: ^(b) McNemar's Test / * p-value < 0.05 (significant result)

Table 3: Comparison of the main deficiencies present at diagnosis and discharge by cure among patients with leprosy living in the metropolitan region between 2009 and 2014 (n=414). João Pessoa, PB, Brazil, 2016.

Types of deficiencies	Diagnosis	Discharge	p-value ^(b)
Eyes			
Ectropion	2	1	p=1.000
Decrease of cornea sensitivity	16	8	p=0.096
Cornea opacity	7	5	p=1.000
Visual acuity	7	8	P=1.000
Nose			
Dryness	37	17	p=0.002*
Wound	21	2	p=0.000*
Hands			
Hypoesthesia	53	48	p=0.522
Ulcer	17	9	p=0.115
Mobile grip	13	12	p=1.000
Rigid grip	2	4	p=0.500
Reabsorption	3	6	p=0.250
Feet			
Hypoesthesia	152	138	p=0.088
Ulcer	21	9	p=0.004*
Mobile grip	2	2	p=1.000
Rigid grip	0	1	p=1.000
Reabsorption	1	2	p=1.000
Loose foot	9	10	p=1.000

Footnote: ^(b) McNemar's test / * p-value < 0.05 (significant result)

Regarding the number of affected nerves (Table 4), it was found the mean 1.10 (\pm 1.45) affected nerves at the diagnosis and 0.80 (\pm 1.30) at discharge, identifying a significant statistical difference ($p=0.000$). It is possible to observe the decrease in the compromise of all nerves from the diagnosis to discharge presenting a significant statistical difference, with the exception of the median nerve ($p=0.056$).

Table 4: Comparison of the affected nerves at diagnosis and discharge by cure among patients with leprosy living in the metropolitan region of João Pessoa between 2009 and 2014 ($n=414$). João Pessoa, PB, Brazil, 2016.

Affected Nerves	Diagnosis	Discharge	p-value ^(b)
Ulnar	118	84	$p=0.001^*$
Radial	60	34	$p=0.002^*$
Median	95	76	$p=0.056$
Fibular	83	56	$p=0.005^*$
Posterior Tibial	102	80	$p=0.034^*$

Footnotes: ^(b) McNemar's test / * p-value < 0.05 (significant result).

DISCUSSION

It was verified in this study a high percentage of individuals presenting LD1 and LD2 both at diagnosis (29.5% and 11.1%) and cure (26.6% and 10.9%). Other studies also pointed this endemic panorama for the Northeast region^(10,13), classified as the third Brazilian region with higher general detection coefficient of cases (23.8/100.000 inhabitants), configuring area of high endemicity and essential in the maintenance of the disease transmission⁽¹⁴⁾.

Despite these indexes and regional differences related to the leprosy load, in general, Brazil has been presenting a decreased tendency of LD2 throughout the years, observing a decrease of 29% in the last ten years (2005-2015)⁽⁶⁾. This situation is also present in the study, through the decreasing line in the temporal evolution analysis in LD2 cases, especially between the years 2013 and 2014.

In comparison to Asiatic countries, Brazil has lower proportions of LD2⁽⁶⁾, which can be the reflex of the extension of the assistance in the basic health attention, providing improvements in disease control services⁽¹⁵⁾.

It is noteworthy that LDs2 are used to compose epidemiologic indicators to assess the National Program of Leprosy Control, in the strength measurement of morbidity, magnitude, and the epidemiological disease profile, besides determining the quality and effectiveness of provided health services⁽¹⁶⁾.

The decrease in the occurrence of new LD2 cases at diagnosis suggests a less late diagnosis that when accompanied by the rate decrease of the detection, it characterizes a reduction of the endemic magnitude over the years⁽¹¹⁾.

These findings corroborate with the activities proposed by the "Integrated plan of strategical actions to eliminate leprosy, filariasis, schistosomiasis, and onchocerciasis as public health issue, trachoma as cause of blindness and control of geo-helminthiasis: action plan 2011-2015", released by the HM with the proposal to eradicate or drastically reduce a load of these diseases and, dealing with leprosy, it emphasizes the increase of early detection and cure in diagnosed cases⁽¹⁷⁾.

Considering the leprosy load in Brazil and in the world and, aiming to reduce it, even more, the current strategy to fight the disease proposed by the World Health Organization has as one of the goals for the year of 2020, the rate reduction of individuals with LD2 for <1 case per million of inhabitants. Within the pillars recommended by the strategy, there is the fight against leprosy and its complications, aiming at early detection

through the active search of cases, the immediate start/adherence to treatment and the improvement of the prevention and management of incapacities⁽¹⁸⁾.

In this perspective, it is noted the importance of the action of a multi-professional team to prevent the appearance/worsening of physical incapacities, highlighting the action of the nurse and physiotherapist. The nurse, through the nursing appointment, is responsible for the monthly care of the patient with leprosy and should supervise the medication administration, to identify signs and symptoms of the disease, to guide the patient about self-care and, to refer the patient to other professionals when necessary⁽¹⁹⁾. The physiotherapist, besides acting in the prevention phase of incapacities, when guidance about the disease is provided, its complications and the self-care, the professional performs the rehabilitation of sequels caused by the disease⁽²⁰⁾.

In the analysis of body sites, the decrease in its compromising showed in this study, was also verified by other authors⁽²¹⁻²²⁾. However, only the nose presented statistical relevance, corroborating with the decrease in dryness and the presence of wounds found in this site.

Although not being quantified to determine the LPD, the nose lesions had importance in the physical aspect due to deformities, as well as, physiological aspect due to the stigma associated to the disease, as it is considered determinant in the interpersonal relationships.

Besides compromising the individual in his body image, the compromising of this region can also change the partial or total respiratory function, interfering in the performance of work and social activities⁽²²⁾. Based on these premises, as well as, in the facility to observe, intuitively, there was more attention with this area.

Considering the scenario of disabilities, the decrease of cutaneous ulcers in the plantar region deserves attention. A frequent complication in leprosy, the poor plantar perforating results of changes in the sensitivity and motricity of the foot, resulting on sensible losses and weakness/paralysis of the muscles, respectively. In its majority, these lesions are located in the areas responsible for the weight support, interfering in the functionality and quality of life of individuals⁽²³⁾.

This finding shows the importance of the physiotherapy action in the accompaniment of patients with leprosy, and dealing with the therapy of cutaneous ulcers, its goal is the stimulation of the healing process of the lesion, reducing its time of exposition and propitiating the early return of the individual to daily activities⁽²⁴⁾. Within the conducts executed in the service, it is possible to mention: The use of a low-intensity laser, the performance of therapeutic exercises, stride re-education and prescription of prostheses and bracing, configuring the physiotherapy as an essential tool for the treatment of consequences of leprosy.

Although it was observed the reduction of most disabilities, it is important to note that at discharge, there was an increase in the number of individuals presenting more severe complications in the hands (rigid grip and re-absorption) and the feet (rigid grip, re-absorption, and loose foot), the most compromised regions. These manifestations are secondary to the compromising of peripheral nerves, and they could be avoided if the diagnosis and treatment were conducted earlier, while the bacillus was limited to superficial nerve endings.

Still, about disabilities, it is possible to observe the identification of lower levels of compromise in the ocular level when compared to other regions. This fact can be explained by the information "NC" (not conducted) registered in few records, especially in the items visual acuity and corneal sensitivity. The limited material

resources are factors configuring the impediment to prevent incapacities⁽²⁵⁾ and might have influenced the assessment of this region.

Analyzing the nerve trunks, except the median nerve, there was a reduction of the neural compromise. A study conducted in a Reference National Center for the treatment of leprosy in the city of Uberlândia/MG also identified the reduction of the nervous compromise in the comparison of diagnosis versus discharge, with a mean of 2.5 affected nerves per patient and, 2.2 at discharge⁽²²⁾. Nevertheless, these results were superior to the ones found in this study.

It is noteworthy that as consequence of the neural lesion, burns, wounds, ulcers, fistulas, atrophies, rigid joints and muscle imbalance can occur⁽²⁾, becoming indispensable for patients to be guided to self-assess daily their body sites and to perform self-care, aiming to prevent the appearance of disabilities or to avoid its worsening. In the meantime, it is possible to cite how activities as: to hydrate and lubricate the skin, to care for nails and callouses, to inspect shoes before wearing them, to use special insoles and adapted shoes, to avoid transiting in dark environments with uneven floors, within others⁽²³⁾.

Considering the implications of the compromise of nerve trunks, it embodies the importance of the clinical findings of the present study, considering that its reduction avoids the triggering of physical sequels. Therefore, although there was the significant decrease in nervous compromise, the quantity of patients who continued with affected nerves after discharge calls attention.

During the post-discharge, the prevention and the management of residual incapacities still are a challenge, considering that after the patients finish the treatment, they are excluded from the active registry and guided by health professionals to return to services in accordance to their needs, therefore, not receiving a systematic follow-up. Therefore, the integration of services in the attention network has fundamental importance to monitor these patients after discharge by cure, avoiding the installation of permanent sequels.

It becomes relevant to still discuss about the gaps found in medical records in relation to LPD assessment, showing a fragility in the service, considering that the assessment data of LPD are used to compose operational indicators of the HM that monitors the progress of leprosy elimination as a public health issue, besides measuring the attention quality in health services⁽¹¹⁾.

The situation aggravates by the fact that the research scenario in a reference center for the leprosy treatment in the State of Paraíba that assumes a qualified, structured team and, ideal equipment to implement public health policies.

Another aspect of the medical records deserving attention was the registry of the presence of atrophy of the first inter-bone space/inter-bone muscles on the hand, a characteristic sign of lesion of the ulnar nerve.

During this study period, the muscle atrophies were not considered for the LPD classification yet, and they started to be incorporated only in guidelines for vigilance, attention and leprosy elimination as a public health issue published by the HM in 2016. In the current classification, patients with muscle atrophies are considered LD2⁽¹¹⁾.

It is still important to highlight that in the new guidelines, muscle strength was also inserted in the LPD determination, in a way that patients with reduced muscle strength there before were not classified in any level

became level one (1). This change allows broader monitoring and consequently, more control of patients, once the neural damage also causes losses in motor functions.

With the incorporation of these modifications related to LPD, it is very likely that the exposed epidemiological reality would suffer a change in its context, considering the increase of patients who would start to present levels one (1) and two (2) for physical disability. The current panorama is formulated based on the under-notification of these levels, once few medical records already discriminated the presence of disabilities which were not considered before in the preconized assessment by the HM.

This data corroborates the importance of proposed changes, as well as, for the development of new research, that from now on will have more strength and basis to demonstrate the real situation in what concerns the effectiveness and quality of attention services to the individual affected by leprosy.

CONCLUSION

In general, it was found LPD improvement, reduction of the compromise of all body sites as well as in most disabilities and decrease of the impairment and of the number of nerves affected when comparing them at diagnosis and discharge by cure. These findings reveal that the assistance conducted in the secondary health attention center in what concerns the prevention of incapacities and the rehabilitation of individuals was satisfactory. Despite the gaps in activities foreseen by policies directed to individuals with leprosy being identified.

The analysis of the temporal LPD evolution in the cut of 2009-2014 also demonstrates progress, considering that throughout the years, there was a reduction in the number of patients presenting LD2 both at diagnosis and discharge by cure. Which can be related to the decrease in the late diagnosis and speed in the readiness in the reference service, despite the research scenario being a center of secondary health attention and, therefore, not performing the active search for patients, regardless of the existence of a health attention network.

Despite the positive aspects mentioned, it is important to emphasize that an expressive part of patients were discharged from the drug treatment presenting affected nerves and/or incapacities level one (1) or two (2). Therefore, with a need of a periodical accompaniment to prevent the appearance/worsening of deformities, which makes us reflect about the need of changes in the current policy destined to this population, as the creation of a protocol to accompany the individuals after the discharge from the polychemotherapy.

The study has limitations due to the fragility found in medical records related to incomplete information referring to simplified assessment of neural functions and complications and LPD determination, which resulted in losses in the design of the real leprosy situation at the studied region.

Considering the changes proposed by the HM since 2016 and, the lack of studies addressing the incapacity theme, there is the suggestion of new studies in reference centers or in the municipal level, as a way to monitor the progresses reached in the search for the leprosy elimination and to guide actions related to prevention, diagnosis, treatment and rehabilitation of physical sequels caused by the disease.

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