




ORIGINAL ARTICLE

Evolution of physical disabilities in patients with leprosy associated with the level of health care

Evolução de incapacidades físicas em pacientes com hanseníase associada ao nível de atenção à saúde

Evolución de las discapacidades físicas en pacientes con lepra asociada al nivel de atención en la salud

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ABSTRACT

Objective: Analyzing the occurrence of physical disability in leprosy according to levels of health care from 2012 to 2021 in Minas Gerais. **Methodology:** A cross-sectional ecological study conducted with 6,524 cases. Dependent variables: degree of physical disability at diagnosis and at discharge. Independent variables: level of care at the time of notification and discharge. McNemar test and Pearson's chi-square test were performed considering a p-value ≤ 0.05 as significant. **Results:** Although most cases were diagnosed with degree of disability zero (59.5%), a significant number presented degrees of disability one (28.2%), at the three levels of care ($p < 0.001$). The increase in the percentage of cases with degree of physical disability zero was more relevant at the primary care level (12%) ($p < 0.001$). **Conclusion:** The high number of cases diagnosed in specialized services and with physical disabilities already present suggests the need for investments in strengthening primary health care to guarantee comprehensive and effective care with a focus on early diagnosis and reducing physical disabilities related to leprosy.

Descriptors: Leprosy; Health Systems; Delayed Diagnosis; Disability Evaluation; Disabled Persons.

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RESUMO

Objetivo: Analisar a ocorrência de incapacidade física em hanseníase segundo níveis de atenção à saúde no período de 2012 a 2021 em Minas Gerais. **Metodologia:** Estudo ecológico transversal, realizado com 6.524 casos. Variáveis dependentes: grau de incapacidade física no diagnóstico e na alta. Variáveis independentes: nível de atenção no momento da notificação e da alta. Foi realizado teste Mc Nemar e Teste Qui-quadrado de Pearson considerando como significativo um p-valor $\leq 0,05$. **Resultados:** Embora a maioria dos casos tenham sido diagnosticados com grau de incapacidade zero (59,5%), um número expressivo apresentou grau de incapacidade um (28,2%), nos três níveis de assistência ($p < 0,001$). O aumento no percentual de casos com grau incapacidade física zero foi mais relevante no nível de atenção primária (12%) ($p < 0,001$). **Conclusão:** O elevado número de casos diagnosticados nos serviços especializados e com incapacidades físicas já instalada sugere a necessidade de investimentos no fortalecimento da atenção primária à saúde para garantia de um atendimento integral e resolutivo, com foco no diagnóstico precoce e na redução das incapacidades físicas relacionadas à hanseníase.

Descritores: Hanseníase; Sistema de Saúde; Diagnóstico Tardio; Avaliação da Deficiência; Pessoas com Deficiência.

RESUMEN

Objetivo: Analizar la ocurrencia de discapacidad física en lepra según niveles de atención a la salud de 2012 a 2021 en Minas Gerais. **Metodología:** Un estudio ecológico transversal realizado con 6.524 casos. Variables dependientes: grado de discapacidad física al diagnóstico y al alta. Variables independientes: nivel de atención en el momento de la notificación y el alta. Se realizaron las pruebas de Mc Nemar y Chi-cuadrado de Pearson, considerándose significativo un valor de $p \leq 0,05$. **Resultados:** Si bien la mayoría de los casos fueron diagnosticados con discapacidad nivel cero (59,5%), un número significativo presentó discapacidad nivel uno (28,2%), en los tres niveles de asistencia ($p < 0,001$). El aumento en el porcentaje de casos con discapacidad física nivel cero fue más relevante en el nivel de atención primaria (12%) ($p < 0,001$). **Conclusión:** El elevado número de casos diagnosticados en servicios especializados y con discapacidad física ya establecida sugiere la necesidad de inversiones en el fortalecimiento de la atención primaria de salud para garantizar una atención integral y resuelta enfocada en el diagnóstico temprano y en la reducción de las discapacidades físicas relacionadas a la lepra.

Descriptorios: Lepra; Sistemas de Salud; Diagnóstico Tardío; Evaluación de la Discapacidad; Personas con Discapacidad.

INTRODUCTION

Leprosy is characterized as a chronic infectious disease caused by *Mycobacterium leprae*⁽¹⁾. It most often affects populations in unfavorable sanitary and economic conditions, being considered a neglected disease. The disease can progress with neuropathy and, consequently, functional loss and physical disabilities, affecting mainly the hands, feet and eyes, a factor related to late diagnosis. Other factors, such as male sex⁽²⁾, high bacillary loads and the appearance of hansenic reactions, may increase the risk of developing physical disabilities in patients affected⁽³⁾.

The relevance of leprosy as a public health problem is due to the physical and social disabilities it causes⁽⁴⁾. The assessment of disability is performed by means of physical examination at diagnosis,

during treatment and discharge. Its purpose is to identify and control the level or degree of loss of sensitivity and/or apparent deformities caused by the disease⁽⁵⁾. The Ministry of Health (MoH) describes the Degree of Physical Disability (DPD) zero when there is absence of changes in the eyes, hands and feet; the DPD one, when there is decrease in strength and/or loss of protective sensitivity in these organs; and DPD two, when there is loss of protective sensitivity associated with the presence of motor complications in the eyes, hands or feet and/or visible deformities⁽²⁾.

Brazil still faces an endemic situation for the disease, occupying the second place in number of cases in the world⁽⁶⁾. In 2022, 19,635 new leprosy cases were diagnosed in the country, of which 2,258 (11.5%) had a degree two of physical disability at the time of diagnosis⁽²⁾. In the epidemiological scenario of the State of Minas Gerais, in the same year (2022), 1,037 cases of leprosy were reported, with 197 (19%) presenting degree two of physical disability at the time of diagnosis, indicating late diagnosis and low effectiveness of health services⁽²⁾.

The health program actions play a key role in this context, directly impacting the risk of illness. This risk involves epidemiological factors that reflect the size and impact of the endemic disease, highlighting the severity and spread of morbidity among the population⁽⁷⁾. There is an interaction between determinants of this scenario, such as socioeconomic conditions, environmental conditions and inequality in access to health, especially among vulnerable groups^(8,9).

Despite efforts to eliminate the disease through global and national strategies^(2,10), and advances in understanding leprosy, with treatment and cure recognized and prescribed in the Clinical Protocol and Therapeutic Guidelines for Leprosy (PTGL)⁽¹¹⁾, barriers are still observed in the services to diagnose the disease. This includes the maintenance of the vertical model of health care, with the usual referral of users to secondary care and the ineffectiveness of counter referencing^(12,13).

At the State level, Minas Gerais has a Network of Care for Persons with Leprosy (NCPL), formed by assistance points in different levels of complexity. This network focuses on integrated and systematized actions, with primary health care (PHC) as the user's gateway⁽¹⁴⁾. However, a study has shown that there is a high number of people treated in specialized services, diagnosed and treated in reference centers⁽¹⁵⁾, suggesting limitations in the performance of PHC. In addition, another study showed that the clinical practice in PHC still faces difficulties related to the diagnosis and treatment of leprosy, as well as to the monitoring of physical disabilities⁽¹⁶⁾. Therefore, it is justified to understand the distribution of the care of leprosy cases within NCPL, as well as the impact on physical disability in these cases.

The objective of this study is to analyze the occurrence of the degree of physical disability in leprosy according to levels of health care, from 2012 to 2021, in Minas Gerais.

METHODOLOGY

Design, study place and period

This is a cross-sectional ecological study, conducted in 853 municipalities of Minas Gerais, located in the Southeastern region of the country. The checklist for presentation of results from observational studies in epidemiology (STROBE) was adopted to comply with methodological rigor.

The study period included the years 2012 to 2021. The selection of this historical series was based on a specific characteristic of the physical disabilities related to leprosy, which present high sensitivity to oscillations in the operational capacity of health services, especially in relation to the competence to meet the demands of the population, ensuring diagnosis, treatment, prevention and adequate follow-up.

Population or sample

The study population was composed of individuals diagnosed with leprosy and notified in the Information System of Notifiable Diseases (ISND) in Minas Gerais, provided by the Coordination of Leprosy of the State Health Department of Minas Gerais (SES/MG) through the Electronic Citizen Information System (e-CIS).

Inclusion and exclusion criteria

The dependent variables were the degree of physical disability at diagnosis and discharge. They were categorized as zero, one and two according to the registration in ISND. The independent variables were the level of attention at the time of notification and at the time of discharge of leprosy, categorized as primary, secondary and tertiary levels, through consultation in the National Registry of Health Establishments (NRHE). This categorization was performed from the name and code of the health unit of notification and the current care health unit, informed at the time of diagnosis and discharge, respectively, available in the ISND database. According to the recommendations of the Ministry of Health: health post, health center and basic health unit were classified as primary level; polyclinic, mixed unit, general and specialized emergency room and isolated offices as secondary level; and hospital in general and specialized diagnosis, such as tertiary level⁽¹⁷⁾.

Inclusion criteria were adopted for sample selection, new case reported with leprosy and type of exit as cure. The cases that did not have the degree of disability evaluated in diagnosis and discharge, those who entered the service by transfers and relapses were excluded, as well as the cases whose health establishment was not found in NRHE and/or that do not fall into the types of service characterized as a care service, with professional qualified to carry out the diagnosis and follow-up of leprosy cases,

For example, epidemiological and environmental surveillance service, municipal health department and psychosocial care centers (CAPS).

The criterion adopted as improvement of DPD are the cases that have evolved from DPD one to DPD zero and from DPD two to DPD one or DPD zero. Regarding the worsening of cases, we considered the evolution from DPD zero to DPD one or DPD two and from DPD one to DPD two. The maintenance of cases was given by the permanence of the same DPD at the time of diagnosis and at discharge.

Analysis of results and statistics

For the treatment of the database and organization of the study variables, Microsoft Excel software (2010 version) was used. Subsequently, the data were exported to IBM SPSS statistical software – 2021 version for organization and creation of the study variable "physical disability evolution" and for the analyses. In the comparison between the degree of physical disability at diagnosis and discharge (table 1), the Mc Nemar test was used and for the evaluation of the association between the evolution of the degree of physical disability and the level of health care, the Pearson chi-square test was applied (tables 2 and figure 1). In relation to the significance level, it was considered a p-value ≤ 0.05 .

Ethical aspects

The present study was conducted in accordance with National Health Council resolution N 466/2012, and as secondary data provided by the Hanseniasis Coordination of the State Health Department of Minas Gerais (SES/MG) were used through the Electronic Citizen Information System (ECIS), without variables that allowed the identification of patients, said resolution waives submission or approval of the Ethics and Research committee.

RESULTS

Between 2012 and 2021, 13,860 cases of leprosy were reported in the State of Minas Gerais. Of these, 6,524 considered the eligibility criteria of this study. Of the total number of cases analyzed, 3,513 (58.8%) were reported by primary level of health care, 2,281 (35%) by secondary level and 730 (11.2%) by tertiary level. The pattern of distribution of the discharge was made up of 3,520 (54%) cases at primary level, 2,301 (35.3%) at secondary level and 703 (10.8%) at tertiary level. The majority of reported cases (N=6,295 - 96.5%) were diagnosed and discharged at the same level of health care.

Table 1 shows the distribution of leprosy by DPD in diagnosis and discharge in Minas Gerais, between 2012 and 2021. It is deduced that there is a statistically significant association ($p < 0.001$) between the degree of disability of patients with leprosy at the time of diagnosis and at the time of discharge. There

were diagnosed 3885 (59.5%) cases with zero DPD, 1839 (28.2%) with one DPD and 800 (12.3%) with two DPD. Among people with zero degree of disability at the time of diagnosis, 3,497 (90%) remained in the same classification at discharge. In contrast, among those who showed DPD two in the diagnosis, 511 (63.9%) had this same classification in high and 143 (17.9%) evolved to zero.

Table 1. Distribution of leprosy cases by degree of disability at diagnosis and discharge in Minas Gerais from 2012 to 2021.

Degree of disability at discharge	Degree of disability at diagnosis								p-value
	Grade zero		Grade one		Grade two		Total		
	n	%	n	%	n	%	n	%	
Grade zero	3497	90.0%	802	43.6%	143	17.9%	4442	68.1%	<0.001
Grade one	314	8.1%	930	50.6%	146	18.3%	1390	21.3%	
Grade two	74	1.9%	107	5.8%	511	63.9%	692	10.6%	
Total	3885	100%	1839	100%	800	100%	6524	100%	

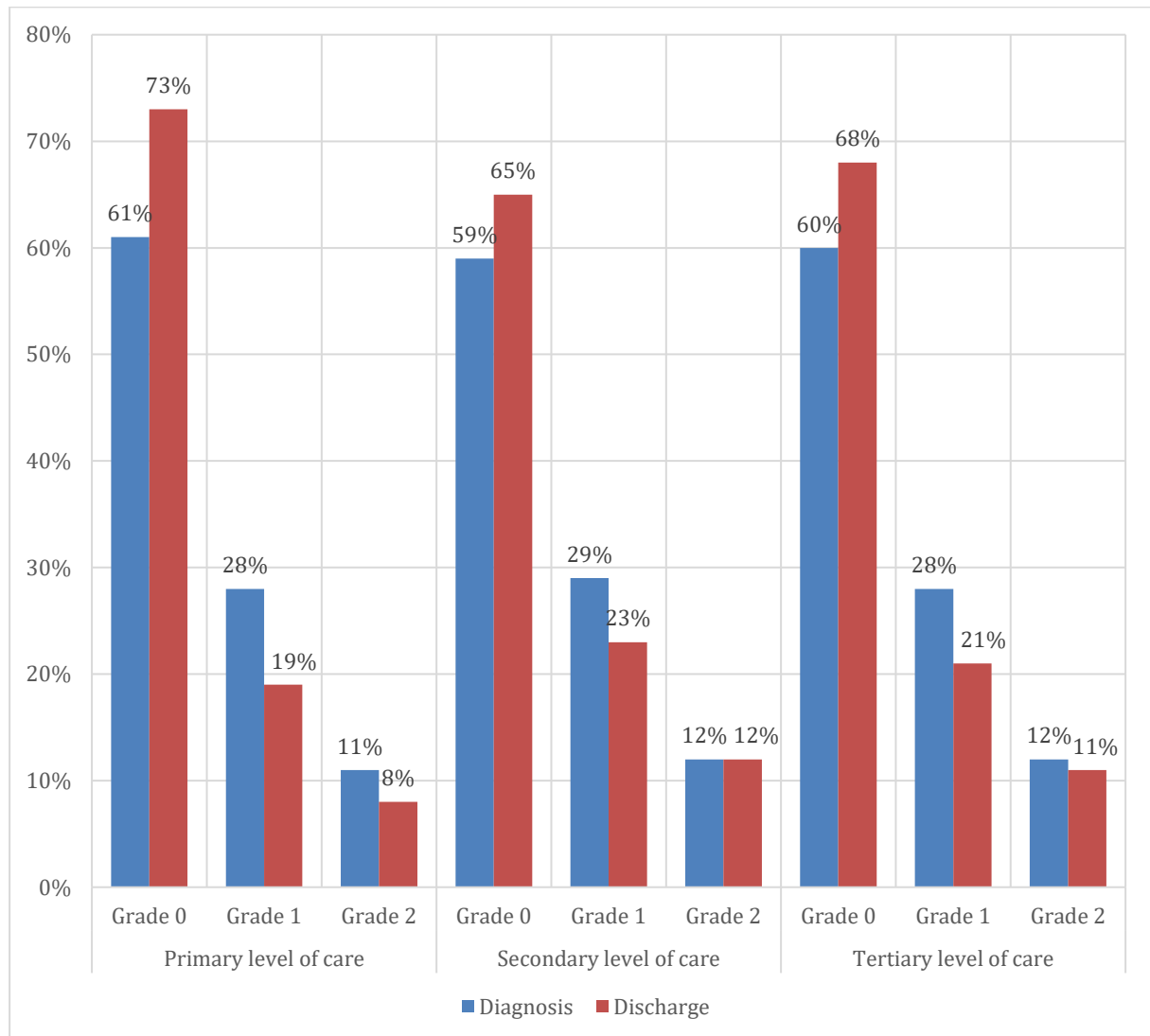
Table 2 shows the evolution of DPD in leprosy patients according to the level of health care at diagnosis in Minas Gerais between 2012 and 2021. There is a statistically significant association between the evolution of DPD and the level of health care at discharge ($p < 0.001$), so that among patients diagnosed with leprosy in primary health care, 204 (5.8%) presented worsening of DPD. Among those diagnosed in secondary health care, 180 (7.8%) presented worsening and among those of tertiary care, 111 (15.8%) evolved with worsening of DPD. The highest prevalence of disability improvement was observed in primary health care ($N=644 - 18.3\%$), while the lowest was recorded in secondary health care ($N=114 - 16.2\%$).

Table 2. Evolution of the degree of disability according to the level of health care in diagnosis in Minas Gerais from 2012 to 2021.

Evolution of the degree of disability	Level of health care at discharge								p-value
	Primary level		Secondary level		Tertiary level		Total		
	n	%	n	%	n	%	n	%	
Improvement in the degree of disability	644	18.3%	333	14.5%	114	16.2%	1091	16.7%	<0.001
Maintenance of the degree of disability	2672	75.9%	1788	77.7%	478	68.0%	4938	75.7%	
Worsening degree of disability	204	5.8%	180	7.8%	111	15.8%	495	7.6%	
Total	3520	100%	2301	100%	703	100%	6524	100%	

When analyzing the variation between DPDs at diagnosis and discharge, as shown in figure 1, a statistical significance was found in the three levels of health care ($p < 0.001$). It is noted that although most cases were diagnosed with DPD zero, a significant number presented DPD two in all levels of assistance. The increase in the percentage of cases with zero DPD was more relevant at the primary care level, when compared to other levels, with an increase of 419 cases (12%) at the discharge. At all levels of care there was a reduction in the number of cases classified as DPD one, this result being more relevant at the primary care level, corresponding to a decline of 309 cases (9%) at discharge. In relation to DPD two, there was a slight variation in the results for primary and tertiary levels of attention and no change occurred at the secondary level.

Figure 1. Comparison of the degree of disability according to the level of health care at diagnosis and discharge in Minas Gerais from 2012 to 2021.



DISCUSSION

The prevalence of leprosy cases detected in PHC, as observed, is consistent with other studies that show a higher percentage of diagnoses at this level of attention^(18,19). These findings reinforce the importance of PHC as the main gateway for diagnosis of the disease, but also demonstrate the ineffectiveness of decentralization of leprosy care, as established by the Operational Standard of Health Care (OSHC-SUS 01/2001)⁽²⁾. There is still a significant proportion of patients being diagnosed and treated at the secondary and tertiary levels (46%), similar to another State in Brazil, which identified a predominance of 97.8% of patients treated in specialized reference centers⁽²⁰⁾. Failure to manage the disease early in PHC leads to referencing suspected cases for diagnosis in units of greater complexity^(12,21).

In addition, there are operational and organizational gaps related to health services, such as the absence of defined flows⁽²²⁾ and the lack of knowledge among primary care physicians about the diagnosis, treatment and follow-up of leprosy⁽²³⁾. The same situation was identified among nurses from primary health units and from the Family Health Strategies^(24,25).

Historically, leprosy has been associated with stigma that negatively impacts both the personal and occupational lives of patients⁽²⁶⁾, and the presence of physical disabilities aggravates these impacts, strengthening the importance of early diagnosis and treatment⁽⁶⁾. In this study, although it was identified that the three levels of health care presented a large percentage of patients with DPD zero, both at diagnosis and discharge, this does not indicate that all cases received adequate assistance, considering that there is a significant portion of patients who have evolved from DPD zero to DPD one and two.

In addition, many patients were diagnosed with the presence of DPD two already installed (12.3%). When analyzing other countries, a higher proportion of DPD 2 in patients with leprosy at diagnosis was reported in Colombia (15%)⁽²⁷⁾ and Ethiopia (30%)⁽²⁸⁾, in contrast to the best result identified in Nigeria (10%)⁽²⁹⁾.

The delay in diagnosis is the main reason for the risk of developing disability (DPD one and two) among adult patients with leprosy^(22,30). A delay of more than three months from the onset of symptoms is an unfavorable indicator in this group of patients⁽³¹⁾. Factors such as socioeconomic difficulties, distance to the health center, and lack of resources or transportation contribute to this outcome^(31,32). Fear of stigma and painless symptoms were highly associated with an average delay in case detection of more than twelve months in a study conducted in Ethiopia⁽²⁸⁾. Therefore, the priority of health services should be the identification and treatment of cases before physical disabilities develop⁽²⁾. This strategy is the most effective to reduce stigma associated with the disease^(33,34).

It is important to emphasize that the physical disability of cases should be evaluated at two points: in the diagnosis and in the discharge for cure⁽⁵⁾. However, this action, which is fundamental in the management of leprosy, is often neglected^(19,21). There are records of a high number of cases in which the disability assessment was "ignored", "not performed" or had the "blank field", either due to failures in filling out the notification form by the health professional, in the data entry or even for assistential weaknesses in the evaluation⁽³⁵⁾. The lack of DPD registration or high proportions of DPD one and two may reflect weaknesses in surveillance programs, late diagnoses and failures in activities related to the interruption of the disease transmission chain⁽³⁶⁾.

Guaranteeing accesses to primary care and, when necessary, to medium- and high-complexity reference units is fundamental, in line with the principle of integrality of SUS. The physical disabilities resulting from leprosy directly reflect the quality of access to diagnosis and follow-up of cases during treatment and after discharge⁽³⁴⁾. This means that health services must go beyond the offer of

polychemotherapy, incorporating strategies that address all dimensions of the disease, including the prevention of physical disabilities and social, family, and cultural aspects^(33,34).

Study limitations

The limitations of this study are related to the use of secondary sources, with possible bias in information and registration. In some data analyzed, there were weaknesses, such as the absence of codes and names of health services in ISND, which may have led to the underestimation of some variables. In addition, the presence of cases that evolved from DPD two to DPD zero in the database suggests misunderstandings in classification, since DPD two indicates the presence of permanent deformities.

Despite these limitations, the use of secondary data is justified by the low cost in conducting the research. However, prospective studies are necessary to evaluate more accurately the progression of patients' disabilities and their trajectory in NCPL through outpatient monitoring.

Contributions to the field of nursing, health or public policy

This study contributes directly to the reflection on the quality of care for patients diagnosed with leprosy not only in Minas Gerais, but throughout Brazil. The nurse, as well as other professionals involved in the care of leprosy cases, must undergo continuing education programs for the diagnosis, monitoring and treatment of leprosy, In addition to the adequate completion of all fields of epidemiological surveillance tools, in order to avoid underreporting and information failures. Finally, the results of this research may support the formulation of more specific and appropriate strategic actions to strengthen leprosy control in primary health care, favoring early diagnosis and prevention of disabilities.

CONCLUSION

Our findings show that PHC plays a crucial role in both the diagnosis and treatment of leprosy, accounting for more than half of all cases diagnosed and treated. However, we highlight that there is a high number of patients undergoing treatment in specialized reference centers, which highlights the persistent challenges of decentralization and prioritization of PHC as the gateway to health service.

The analysis revealed that, although most patients were diagnosed without any physical disability, a high number of cases presented late diagnosis, with disabilities already installed in all levels of care. This suggests the existence of gaps that compromise the quality of care, such as weaknesses in the reference and counter-reference system, difficulties in accessing health services and early management of the disease. In addition, the significant number of patients who maintained DPD one indicates the need for more robust strategies to prevent permanent sequelae.

Therefore, the results of this study highlight the need for investments in professional training and strengthening PHC as a gateway to NCPL, ensuring an integral and decisive service. The reduction of physical disabilities related to leprosy should be a priority for the health system, in order to minimize the social and economic impact of the disease, as well as reduce the stigma that still persists.

Future studies, preferably prospective in nature, are recommended to monitor the evolution of disabilities during treatment and after discharge, allowing a better understanding of patients' needs and the adequacy of public health policies.

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