

Sociodemographic and epidemiological characteristics related to the degree of physical disability in leprosy in the state of Paraíba, Brazil

Características sociodemográficas e epidemiológicas relacionadas ao grau de incapacidade física em hanseníase no estado da Paraíba, Brasil

Características sociodemográficas y epidemiológicas relacionadas con el grado de discapacidad física en la lepra en el estado de Paraíba, Brasil

Gerlane Cristinne Bertino Vêras^{ID¹}, Luiz Henrique da Silva^{ID²}, Wagner Maciel Sarmiento^{ID³}, Ronei Marcos de Moraes^{ID⁴}, Simone Helena dos Santos Oliveira^{ID⁵}, Maria Júlia Guimarães Oliveira Soares^{ID⁶}

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CONTACT INFORMATION:

Gerlane Cristinne Bertino Vêras
Federal University of Campina Grande/
Federal University of Paraíba
E-mail: gerlaneveras2@gmail.com

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¹ Ph.D. student in the Graduate Program in Nursing at the Federal University of Paraíba, João Pessoa, Paraíba, Brazil. Teacher of Teacher Training Center, Academic Unit of the Technical Health School of Cajazeiras, Federal University of Campina Grande, Paraíba, Brazil.

² Ph.D. student in the Graduate Program in Decision Models and Health at the Federal University of Paraíba, João Pessoa, Paraíba, Brazil.

³ Specialist in Primary Care and Family Health by the Multiprofessional Residency Program in Jaboaão dos Guararapes, Pernambuco, Brazil. Nurse at Recife Municipal Health Secretariat, Pernambuco, Brazil.

⁴ Ph.D. in Applied Computing by the National Institute for Space Research, São José dos Campos, São Paulo, Brazil. Associate Professor at the Federal University of Paraíba, João Pessoa, Brazil.

⁵ Post-Doctorate at the University of Pernambuco, Recife, Brazil. Full Professor at the Professional and Technological Center, Technical School of Health at the Federal University of Paraíba, João Pessoa, Paraíba, Brazil.

⁶ Ph.D. in Nursing by the Federal University of Ceará, Fortaleza, Brazil. Retired Professor at the Federal University of Paraíba, João Pessoa, Paraíba, Brazil

ABSTRACT

The objective was to analyze the association between sociodemographic and clinical characteristics with the development of physical disabilities of grades 1 and 2 in people diagnosed with leprosy in Paraíba, Brazil. It's



an ecological study, population-based, which had the 223 municipalities at the Center of Chronic and Neglected Diseases/Leprosy belonging to the Health Surveillance Executive Management of the Health Department of Paraíba State in June 2021, after extraction from the Notifiable Diseases Information System. The database gathered 2,468 new cases of leprosy registered in the period from 2016 to 2020. The probability of a person diagnosed with leprosy developing physical disability 1 or 2 is greater in males, aged 15 or over, with formal education less than or equal to nine years, multibacillary classification, with more than five lesions, and more than one affected nerve, in addition to positive bacilloscopy. Health education policies are strongly recommended to improve the knowledge of professionals and the community. Approaches about leprosy, early diagnosis, active search, surveillance, and follow-up of cases and their contacts, in addition to physical disabilities, especially for people who are more vulnerable to developing them, are fundamental.

Keywords: *Leprosy. Disabled Persons. Primary Health Care. Epidemiology. Health Profile.*

RESUMO

Objetivou-se analisar a associação entre características sociodemográficas e clínicas com o desenvolvimento dos graus de incapacidades físicas 1 ou 2 em pessoas com diagnóstico de hanseníase na Paraíba, Brasil. Estudo ecológico, de base populacional, que teve como unidades de análises os 223 municípios do estado. Os dados foram coletados no Núcleo de Doenças Crônicas e Negligenciadas/Hanseníase, pertencente à Gerência Executiva de Vigilância em Saúde da Secretaria de Saúde do estado da Paraíba em junho de 2021, após extração do Sistema de Informação Nacional de Agravos de Notificação. O banco de dados reuniu 2.468 casos novos de hanseníase registrados no período de 2016 a 2020. A chance de uma pessoa diagnosticada com hanseníase desenvolver a incapacidade física 1 ou 2 é maior nas pessoas de sexo masculino, com 15 anos ou mais, estudo formal menor ou igual a nove anos, classificação operacional multibacilar, com mais de cinco lesões e mais de um nervo afetado, além de baciloscopia positiva. Políticas de educação em saúde são fortemente recomendadas no intuito de melhorar o conhecimento dos profissionais e da comunidade. Abordagens sobre a hanseníase, diagnóstico precoce, busca ativa, vigilância e acompanhamento dos casos e de seus contatos, além das incapacidades físicas, em especial para pessoas de maior vulnerabilidade a desenvolvê-las, são fundamentais.

Palavras-chave: *Hanseníase. Pessoas com Deficiência. Atenção Primária à Saúde. Epidemiologia. Perfil de Saúde.*



RESUMEN

El objetivo fue analizar la asociación entre características sociodemográficas y clínicas con el desarrollo de discapacidad física grados 1 o 2 en personas diagnosticadas con lepra en Paraíba, Brasil. Se trata de un estudio ecológico, de base poblacional, cuyas unidades de análisis fueron los 223 municipios del estado. Los datos fueron recogidos en el Centro de Enfermedades Crónicas y Desatendidas/Lepra, perteneciente a la Gerencia Ejecutiva de Vigilancia Sanitaria de la Secretaría de Salud del Estado de Paraíba, en junio de 2021, tras su extracción del Sistema Nacional de Información de Enfermedades de Declaración Obligatoria. La base de datos recogió 2.468 nuevos casos de lepra registrados en el período de 2016 y 2020. La probabilidad de que una persona con lepra desarrolle discapacidad física 1 o 2 es mayor en personas del sexo masculino, con 15 años o más, con menos o igual a nueve años de educación formal, clasificación operativa multibacilar, con más de cinco lesiones y más de un nervio afectado, así como baciloscopia positiva. Las políticas de educación sanitaria son muy recomendables para mejorar los conocimientos de los profesionales y de la comunidad. Es fundamental el abordaje de la lepra, el diagnóstico precoz, la búsqueda activa, la vigilancia y el seguimiento de los casos y sus contactos, así como de las discapacidades físicas, especialmente para los más vulnerables a desarrollarlas.

Palabras clave: Lepra. Personas con Discapacidad. Atención Primaria de Salud. Epidemiología. Perfil de Salud.

INTRODUCTION

Leprosy is a millenary disease, characterized as a neglected tropical disease. It continues to be actively transmitted in several countries around the world, 23 of which are considered priority countries, such as India, Brazil, and Indonesia. These countries are responsible for about 74.5% of the total cases registered in 2021 (140,594), each with over 10,000 reported cases¹.

As a dermato-neurological disease, it has a great disabling potential, therefore, it is essential to assess the degree of physical disability (GIF) at diagnosis so that measures can be taken to minimize possible physical and psychosocial damage to the affected person². Besides, promising results of preventive measures are configured as an indicator of the effectiveness of actions and the population's access conditions to leprosy control services³.

The GIF classification related to leprosy is determined by the World Health Organization (WHO) in GIF 0, when there is no disability in eyes, hands, or feet; GIF 1, when there is a decrease in muscle strength and/or sensitivity; and GIF 2,

when there is a visible disability, such as lagophthalmos, muscle atrophy, clawing hands and/or feet⁴.

In 2021, Brazil notified 24,083 new cases (NC) of leprosy, of which 2,586 (10.7%) presented GIF 2 at diagnosis, with heterogeneous distribution among regions, states, and municipalities. In the same year, the Northeast ranked first among the regions, both in total number of cases (10,840 – 45.0%), and in those with GIF 2 (972 – 9.0%). Paraíba ranked sixth in the number of NC (527 – 4.9%) and GIF 2 at diagnosis (53 – 10.1%)⁵.

However, the data mentioned above may not represent the true epidemiological situation due to the occurrence of the Coronavirus disease – 19 (COVID-19) pandemic, caused by *Severe Acute Respiratory Syndrome Coronavirus 2* (Sars-CoV-2), which limited the population's access to health services and made it impossible for professionals to act both in the search and the follow-up/treatment of the problem since the beginning of 2020^{6,7}.

The described context highlights the importance of professionals having knowledge about leprosy and its contributing factors for the development of physical disabilities according to each location, to minimize weaknesses in the detection and treatment of cases. Hereupon, this study aims to analyze the association between sociodemographic and epidemiological characteristics with the development of GIF 1 or 2 in people diagnosed with leprosy in Paraíba.

MATERIALS AND METHODS

This is an ecological population-based study carried out in Paraíba. A total of 223 municipalities were used as units of analysis and the Chronic Care for Neglected Infectious Diseases: Leprosy/Hansen's Disease was used as the data collection site, belonging to the Health Surveillance Executive Management of the Health Secretariat of Paraíba State, Brazil, after extraction in the Notifiable Diseases Information System (SINAN), in June 2021.

The consulted database registered 2,491 NCs of leprosy in the period from 2016 to 2020. However, 2,468 were considered eligible for evaluation due to exclusion criteria: misdiagnosis (19 cases) or lack of registration from the municipality of origin (4 cases).

It should be noted that, due to lack of registration, cases were lost, as follows: 568 in the variables gender, age group, and classification; 720 in scholarship; 636 in area of residence; 679 in number of skin lesions, 868 in number of affected nerves (thickened and/or in pain); and 1,361 in bacilloscopy.

For the association analysis between variables (*Odds ratio*) and the statistical significance test (Chi-square), the *Epi Info* software, version 7.2 e *Bioestat* 5.3 was used. In all conclusions obtained through inferential analyses, a significance level of $p < 0.05$ was considered.

This study was previously submitted and approved by the Research Ethics Committee of the Federal University of Paraíba, under judicial opinion nº. 4.620.491, respecting the Regulatory Guidelines and Norms for Research Involving Human Subjects, following Resolutions Nº 466/2012 and 510/2016 of the National Health Council (CNS)^{8,9}.

RESULTS

A total of 2,468 cases of leprosy were analyzed, distributed by year and GIF in Table 1.

Table 1 – Distribution of leprosy cases by degree of physical disability and year of notification, from 2016 to 2020, in the state of Paraíba, Brazil.

GIF	Year (%)					Total (%)
	2016	2017	2018	2019	2020	
GIF 0	256 (20.3)	258 (20.5)	276 (22.0)	305 (24.2)	163 (13.0)	1,258 (51.0)
GIF 1	81 (18.3)	104 (23.5)	106 (23.9)	99 (22.3)	53 (12.0)	443 (17.9)
GIF 2	35 (17.6)	45 (22.6)	47 (23.6)	48 (24.1)	24 (12.1)	199 (8.1)
SR/SA*	80 (14.1)	71 (12.5)	100 (17.6)	161 (28.3)	156 (27.5)	568 (23.0)
Total	452 (18.3)	478 (19.4)	529 (21.4)	613 (24.8)	396 (16.1)	2,468 (100)

Note: *No registration/no evaluation.

Source: Elaborated by the authors.

Table 1 shows that occurred a increase in total number of cases between 2016 and 2019. In 2017 increased approximately 5.8%; 2018, 10.7%; and 15.9% in 2019. The other hand was observed a reduction of 35.4%, in 2020. The same occurred for cases with GIF 0, (0.8% in 2017; 7.0% in 2018; 10.5% in 2019, and a reduction of 46.6% in 2020).

Regarding the cases with GIF 2 was observed increased (28.6% in 2017; 4.4% in 2018; 2.1% in 2019; and a reduction of 50.0% in 2020). The number of cases with GIF 1 increased between 2016 and 2018 (28.4% in 2017; and 1.9% in 2018) and a reduction in 6.6% in 2019, and 46.5% in 2020.

However, for cases without registration or without GIF evaluation, there was a reduction in the number between 2016 and 2017 (11.2%); increase in 2018 and 2019 (40.8% and 61.0%, respectively), and a subsequent reduction in 2020 (3.1%).



Of the total number of reported cases, 1,900 (77.0%) were evaluated for GIF at diagnosis and associated with sociodemographic and epidemiological variables, as can be seen in Table 2.

Table 2 – Association between notified NC of leprosy according to the degree of physical disability and sociodemographic and epidemiological variables, from 2016 to 2020, in the state of Paraíba, Brazil.

Variables	GIF 0	GIF 1	GIF 2	OR (IC)	P
Gender					
Male	625	266	140	1.52 (1.22 – 1.90)*	< 0.05
Female	633	177	59	2.40 (1.74 – 3.32)**	
Total	1,258	443	199		
Age					
< 15 years	84	14	3	0.46 (0.26 – 0.81)*	< 0.05
≥ 15 years	1,174	429	196	0.21 (0.07 – 0.70)**	
Total	1,258	443	199		
Education (completed years)					
≤ 9	697	351	155	3.80 (2.82 – 5.11)*	< 0.05
> 9	460	61	24	4.3 (2.73 – 6.66)**	
Total	1,157	412	179		
Area of residence					
Urban	1,045	367	152	0.98 (0.72 – 1.36)*	> 0.05*
Rural	168	60	40	0.61 (0.42 – 0.90)**	< 0.05**
Total	1,213	427	192		
Classification					
Multibacillary (MB)	679	370	184	4.32 (3.30 – 5.70)*	< 0.05
Paucibacillary (PB)	579	73	15	10.46 (6.11 – 17.91)**	
Total	1,258	443	199		
Number of Lesions					
≤ 5	746	147	51	0.34 (0.30 – 0.43)*	< 0.05
> 5	456	266	123	0.25 (0.18 – 0.36)**	
Total	1,202	413	174		

Variables	GIF 0	GIF 1	GIF 2	OR (IC)	P
Affected Nerves					
None	882	80	21	0.05 (0.04 – 0.06)*	< 0.05
≥ 1	161	305	151	0.03 (0.02 – 0.04)**	
Total	1,043	385	172		
Bacilloscopy					
Positive	292	158	70	1.80 (1.36 – 2.37)*	< 0.05
Negative	418	126	43	2.33 (1.55 – 3.50)**	
Total	710	284	113		

Note:*Referring to the association of variables regarding GIF 0 and GIF 1; ** referring to the association of variables regarding GIF 0 and GIF 2.

Source: Elaborated by the authors.

It was possible to see in Table 2 that the chance of a person developing GIF 1 or 2 is approximately 2-fold in males with positive bacilloscopy; and with up to 9 years of formal study, it increases about 4 times. MB individuals have an approximately 4-fold increase to develop GIF 1 and a 10-fold increase for GIF 2.

On the other hand, if the age group variables are less than 15 years old and the patient has up to 5 lesions and no affected nerves, the chance of developing physical disabilities is reduced, thus, being 15 years old or older increases the chance of developing GIF 1 in 2 times and GIF 2 in 5 times; having more than 5 lesions increases 3 times the chance for GIF 1 and 4 times for GIF 2; and having an affected nerve increases the chance of developing GIF 1 by 20 times and the chance of developing GIF 2 by 33 times.

The housing area did not present a significant association with the development of GIF 1 or 2.

DISCUSSION

In Brazil, leprosy is still an important public health problem, despite the programs and strategies established for its control. A condition that places the country in second place in the number of NCs notified in the world and in the number of people who present GIF 2, at the time of diagnosis¹. Paraíba does not differ from the national reality.

Results reveal a high incidence of leprosy cases between 2016 and 2019, as opposed to the 35.4% decrease identified in 2020. This finding may be due to the social isolation determined by the COVID-19 pandemic, which suggests that the 2020 data may not reflect the reality of Paraíba, Brazil, and the world^{6,8}.

In this way, the Initiative *Sasakawa* for leprosy stands out for organizing the campaign “*Don’t forget Hansen’s disease*”, with the participation of non-governmental organizations, people affected by the disease, research institutes, and government agencies from several countries, whose objective is to develop awareness and communication activities in partnership with governments, so that they do not forget leprosy, even if the COVID-19 is a central concern for the country. In Brazil, the campaign is run by groups of the Movement for the Reintegration of Persons Affected by Hansen disease (Morhan)¹⁰.

Results show that 17.9% of the cases had GIF 1 and 8.1% had GIF 2, which makes it possible to state that when the diagnosis is late, either due to factors such as lack of knowledge about the disease and/or delay in confirming the diagnosis, in addition to the lack of management oversight, increases the risk of leprosy complications.

Regarding the greater chance of male individuals developing physical disability, the findings corroborate with national and international studies¹¹⁻¹⁵, and may be related to the fact that men have a low demand for health services when first symptoms/signs appear and/or for proper monitoring of the condition¹⁶.

As for the age group, it was observed that in individuals aged 15 years or older, there is a greater chance of developing physical disability, and this can be explained by the leprosy pathological process being slow¹⁷ and diagnosis being performed, many times, late. In addition, cases in individuals younger than 15 years old also represent the hidden prevalence of cases, active transmission chain, and high endemicity of the disease in the locality^{12,18-19}.

Evaluating the household contacts of people diagnosed with leprosy is fundamental for breaking the chain of transmission of the disease, given the possibility of an early diagnosis of a NC or the referral and guidance of the person regarding the adoption of preventive measures, such as the use of health education, BCG vaccination, and 5-year follow-up.

Studies carried out in India²⁰ and Brazil²¹⁻²³ associate the development of physical disability in leprosy with a lower number of years of formal study, as also detected in this investigation. Evidence of this nature makes it possible to suggest that people with a lower degree of formal education may have insufficient knowledge and/or precarious financial conditions that hinder the search for health services to carry out an early diagnosis and its due follow-up.

In this regard, Paraíba is at risk for the development of physical disability related to leprosy, as there are many people with formal education of up to nine years, as shown by the Brazilian Institute of Geography and Statistics (IBGE) in the 2010 Census and by the Continuous National Household Sample Survey (2019)²⁴. In this way, it is necessary to carry out continuous health education with the population to minimize this situation in the state.

Regarding the area of residence, there was no statistical significance for the development of GIF 1 and low relevance for GIF 2. Many studies attest a lack of relationship between the region of residence and physical disability resulting from leprosy^{12,23}. However, it is known that the closer the users live to health services, whether in basic or specialized care, the lower the risk of aggravation of the disease, due to improved access and early initiation of treatment/monitoring of cases¹⁴.

It was possible to verify the prevalence of MB cases in people with GIF 1 or 2, a finding that confirms the evidence of previous studies^{12,22}. Attention and investigation of possible weaknesses in health services are suggested concerning the detection and follow-up of leprosy cases and their contacts, as well as for GIF evaluation, especially since MB cases are more likely to develop leprosy reactions, which effectively contribute to the development of physical disabilities.

Leprosy reactions are caused by an immune response triggered by the body against the etiological agent, *Mycobacterium leprae*, which can occur before, during, and after multidrug therapy (MDT), which results in lesions and irreversible nerve damage, when not recognized and adequately treated²⁵.

Having more than 5 lesions, having an affected nerve, and positive bacilloscopy are related to the MB classification, factors that directly contribute to the development of physical disability^{26,27}.

There is also a relevant number of leprosy cases that were not evaluated in GIF diagnosis, as well as a lack of relevant information such as education, area of residence, number of lesions, and bacilloscopy results, to establish a more faithful profile of the association of sociodemographic and epidemiological factors with GIF, as verified in the study by VÉras et al²³, a situation that signals the existence of possible weaknesses in health services focused on leprosy and the lack of supervision by managers.

The evaluation of GIF in the diagnosis is essential for planning and carrying out actions to prevent more severe sequelae of leprosy, but also, to monitor its evolution²⁵. In addition, GIF 2 is used as an epidemiological and operational indicator, and the reduction of cases to this degree is part of the goals of the Global Leprosy Strategy 2021-2030¹⁸.

It is imperative to state that health teams must be competent and responsible for carrying out actions aimed at the early diagnosis of leprosy and adequate treatment, to prevent the development of physical disabilities, as well as carrying out contact surveillance and health education²⁸.

In addition, the existence of dignified working conditions is fundamental for work development in an assertive way and that results in the achievement of proposed objectives, whether in the perspective of interpersonal relationships, availability of human and material resources, physical structure, in addition to other aspects of the physical and organizational environment²⁹.



It should be noted that health professionals from leprosy services must organize themselves not only for diagnosing and offering MDT but in all aspects involving the disease³⁰.

It is also noteworthy that the leprosy situation in the state remains problematic. Despite being a millennial disease, negligence prevails, especially as it affects the most socially vulnerable people, and which was aggravated by COVID-19, generating concern from entities and people involved with the cause.

CONCLUSION

The development of GIF 1 or 2 in people with leprosy in Paraíba is more prevalent in male individuals, aged 15 years or more, formal study less than or equal to nine years, MB classification, with more than five lesions and more than one affected nerve, in addition to positive bacilloscopy.

Health professionals must be provided with favorable working conditions and the establishment of public policies in education about leprosy, with emphasis on active and early search for cases, use of MDT and GIF evaluation, as well as for the community in general; for people who are more vulnerable to developing physical disabilities.

It is recommended that continuous research be carried out to properly monitor leprosy epidemiological situation, to plan strategies aligned with local reality.

As a limitation, there is a lack of records when notifying leprosy, which can interfere with the assessment of the epidemiological profile of cases.

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