# 18 - EVALUATION OF THE DISABILITY DEGREE OF PATIENTS WITH A DIAGNOSIS OF LEPROSY

CARLOS CESAR SILVA ALVES
SANDRA EUGÊNIA BARRETO PEREIRA ROJAS
GUÊDIJANY HENRIQUE PEREIRA
DIANA NUNES DA SILVA
ELISMAR PEDROZA BEZERRA
TAMARA MARIA DE FREITAS COELHO
Hospital Universitário Lauro Wanderley - HULW – Paraíba, Brasil
guedijany@gmail.com

doi:10.16887/90.a1.18

### INTRODUCTION

The involvement of peripheral nerves is the main characteristic of leprosy, giving it a great potential to cause physical disabilities that may even develop into deformities (PUCCI et al., 2011). These may cause some problems, such as decreased working capacity, limitation of social life, psychological problems, as well as contributing to the stigma and prejudice of the disease (BRAZIL, 2002).

Although it is an unimportant disease with regard to mortality, the real severity of leprosy appears when we consider the problem of disabilities that it produces. About 20% of all new cases have disabilities at the time of diagnosis, and another 15% will develop them even if all health actions are performed properly (RAMOS; SOUTO, 2010).

Leprosy causes great damage to daily life and interpersonal relationships, causing suffering that goes beyond pain and discomfort strictly linked to physical impairment, with great social and psychological impact (MARTINS; TORRES; OLIVEIRA, 2008). The impact of disability for the patient on their physical and social function is variable: a person with severe disability can continue to perform their daily living activities without major problems and, for others, minimal disability makes social life difficult (RODINI et al., 2010).

It is noteworthy that the number of patients with some degree of disability is increasing at the time of diagnosis of the disease. In this regard, the Ministry of Health warns that the services should assess and determine the degree of disability of leprosy patients at the time of diagnosis, during treatment at least once a year and at discharge (ALVES et al., 2010). Through this evaluation a frequency curve of the different degrees of disabilities can be constructed. Such data may highlight priorities in the prevention and treatment of disabilities, as well as providing support for the development of care plans for leprosy patients.

The frequency of the evaluation contributes to the early diagnosis of neural involvement, as well as to monitor the evolution of this neurological condition, helping both drug treatment and physiotherapy treatment. Moreover, it is important due to the large occurrence of silent neurites, which must be constantly investigated (GONÇALVES; SAMPAIO; ANTUNES, 2009). Sensory and motor impairments, affected by silent neuritis, most often cause severe functional losses without the patient having any complaints of pain.

The proportion of new leprosy cases evaluated at the time of diagnosis and cases cured in the year with the degree of physical disability assessed, according to Ministry of Health Ordinance No. 3125/2010, serve as an indicator of the quality of actions and services, serving parameter to measure the quality of care in health services and monitor the outcome of the Program of Health Surveillance Actions - PAVS (BRAZIL, 2009).

According to the parameters observed in Ordinance No. 3125/2010, a site presents a "good" indicator for the assessment of the degree of disability if at the time of diagnosis their values are greater than or equal to 90%; "regular" situation when the indicator is less than 90 and greater than or equal to 75% and a "precarious" situation when the indicator is less than 75% (RIBEIRO et al., 2012).

If peripheral nerve changes are not properly identified, monitored, and controlled, eye, hand, and foot deformities and disabilities may result. However, if sensory-motor changes are treated early, physical disabilities can be minimized, preventing the spread of functional losses (RODINI et al., 2010).

Patients who arrive without any kind of disability, who are monitored and guided throughout the treatment, have a great chance of preventing the onset of disability when performing the actions proposed by the professionals. Patients who arrive at the service with late diagnosis often have irreversible lesions. In these, preventive measures prevent the aggravation of damage resulting from the established injury and subsequent damage (NARDI; PASCHOAL; ZANETTA, 2005).

For Nursing, it is important to evaluate the degree of disability, as the evaluation and registration of disabilities are primordial activities for the education and promotion of self-care, aiming to avoid the installation of post-discharge disabilities. The assessment of the degree of disability helps to intervene in the process of attention to the person affected by leprosy, with the purpose of preventing physical disabilities and in order to refocus strategies and ways of caring, treating and monitoring individual and collective health (SILVA). SOBRINHO, 2007). It is important for the health team to be aware of the disabilities caused by leprosy because, like many other diseases that are preventable and are not, end up burdening treatment costs and, especially, cause severe physical and emotional sequelae to the patient. (NARDI, PASCHOAL, ZANETTA, 2005).

Based on the considerations, the question is: what is the degree of involvement of leprosy patients? Given the above, the present study aimed to evaluate the degree of disability of leprosy patients.

## **METHODOLOGY**

It is a descriptive, observational and retrospective study. The research scenario was a database of a public hospital, located in the city of João Pessoa, Paraíba. This institution is considered a reference in the care of individuals with infectious diseases.

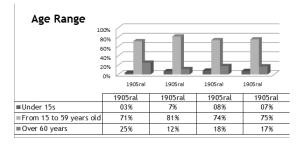
The population defined in the research was composed of all leprosy patients notified by the Epidemiological Surveillance of the referred hospital in the period from 2009 to 2012. It should be noted that regarding the inclusion criteria, all patients diagnosed with leprosy who had undergone leprosy were considered eligible. all the follow-up of the treatment in the service herein exposed. Thus, the sample consisted of 458 records of the Disease Information and Notification Information System (SINAN-NET) of said service, in the period mentioned.

Data collection was performed between September and October 2013, together with the control forms contained in SINAN-NET of patients treated with leprosy diagnosed at the reference service. To obtain the empirical material, a pre-structured

instrument was used, containing the following variables for its characterization: gender, age, municipality of residence, clinical classification of leprosy and, to achieve the proposed objective, degree of disability at the time of diagnosis. and healing. These data were collected through the use of the Tabwin32 program, descriptively tabulated in graphs and tables, and then analyzed

### RESULTS AND DISCUSSION

Regarding the distribution by sex, it was observed that the male gender prevailed in all evaluated years, presenting 75 (63%) cases in 2009, 52 (60.5%) in 2010, 79 (54.9%) in 2011. and 57 (52.3%) in 2012. The years from 2009 to 2012 presented results consistent with the literature1,6,7,12,13, where the highest incidence of leprosy was in males, with 263 (57,4%). %) evaluated cases. In this context, it can be inferred that men have greater social contact with same-sex people, less concern with the body and aesthetics when compared to women (MELÃO et al., 2011). Thus, because there are more health actions aimed at the female public, women have more opportunity to care for themselves.

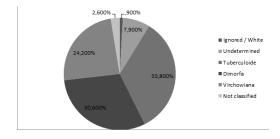


Graph 1: Incidence of leprosy cases by age group.

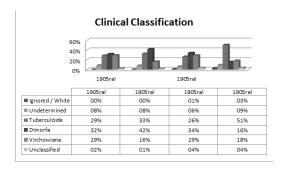
Regarding the age group, it was observed in graph 1 that most people affected by the disease are aged 15 to 59 years, with 71.4% cases in 2009, in 2010 there was an increase to 81, 4%, but in 2011 it fell to 73.6%, remaining on average in 2012 with 75.2% of cases. This tells us that the economically active population is the most affected by leprosy, which can harm the state's economy, since this population may develop disabilities, injuries, reaction states, move away from productive activity and generate a social cost too (MIRANZI; PEREIRA; NUNES, 2010).

The reduction of cases in children under 15 years is a priority of the National Leprosy Control Plan, emerging as an indicator of leprosy in the Growth Acceleration Program (PAC) - Mais Saúde. In this study, we found 30 cases of leprosy in children under 15 years, during the four years of research, which reflects that the detection of cases in this age group is related to recent disease, and active foci of transmission, and its epidemiological follow-up is relevant for leprosy control (BRAZIL, 2009).

Because it has a long incubation period (two to five years), the occurrence of leprosy in children under fifteen reflects early and intense exposure to a high bacillary burden, which leads to illness, despite apparently adequate immunity. In this age group, the detection of new cases is therefore considered an alert event regarding active and recent transmission, pointing to the need for epidemiological surveillance activities and immediate investigation in order to search for the source case (SOUZA, 2011)



Graph 2: Proportion of leprosy cases according to clinical classification..



Graph 3: Incidence of leprosy cases according to clinical classification.

In the selected sample, the undetermined form was the least identified, with 36 (7.9%) cases in all the years studied, and the tuberculoid was the most prevalent with 155 (33.8%), followed by the dimorph represented by 140 (30.6%) cases, and soon after we highlight the virchowiana presenting 111 (24.2%) cases. Analyzing Graph 2, it can be observed that 16 (3.5%) cases did not have their clinical form classified.

Looking at graph 3, it is possible to detect a predominance of the tuberculoid form (50.5%) in 2012, surpassing the dimorphic form (15.6%), which was more prevalent in the other years. The disease initially manifests itself as an undetermined or tuberculoid form, which, due to its low bacillary load, is not contagious, leaves no sequelae, and is curable. When not treated they

may evolve to dimorphic and virchowian forms (BEZERRA, 2011).

Looking at graph 5, it is possible to verify that the numbers of cases that presented dimorphic and virchowian clinical form are high, therefore, it is necessary to closely monitor these patients, checking for signs of neural damage, since most of them may develop sequelae that may lead to can be disfiguring, mutilating and disabling (SOARES; CLEMENTINO; SILVA, 2013).

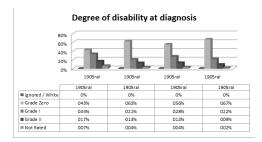
Regarding the municipality of residence, it was found that the city of João Pessoa emerged with the largest number of cases throughout the period, followed by the municipalities of Bayeux, Santa Rita and Sapé. It is important to note that although some regions have already reached the elimination target, the northeast still has high levels of cases of the disease (BRAZIL, 2010). In this sense, such data point to the need for increased actions aimed at intensifying early detection of cases, emerging such aspect as something alarming, since this municipality is considered a reference in the treatment of the disease. Thus, the present findings confirm the need for more effective activities in leprosy control in the municipalities studied.

Regarding the degree of disability assessed at the time of diagnosis, 2012 revealed the highest percentage with 98.2%, followed by 2011 and 2010, both with 96.5% and 2009 with 93.3%. Thus, based on the parameters of Ordinance No. 3125/2010, the site submitted to the study was in "good" condition during the years studied, as its values were above 90%.

Analyzing the data obtained during the time of cure, it was found that out of 119 patients who were diagnosed in 2009 and subsequently discharged, 102 (85.7%) were evaluated at the time of cure. In 2010, out of a total of 86 patients who were later diagnosed and discharged, 69 (80.3%) were evaluated. In 2011, we found a total of 144 diagnosed patients who were subsequently discharged, where 118 (81.9) were evaluated. And in 2012, out of 109 patients who were diagnosed and discharged after treatment, 92 (84.4%) were evaluated at the time of cure.

Based on the parameters of Ordinance 3125/2010, the study site is in "regular" condition in the years studied with regard to evaluation at the time of cure.

In Brazil, the vast majority of patients do not have disabilities at the onset of the disease. Thus, patients with some degree of disability may mean late detection of the disease (RAMOS; SOUTO, 2010). Through the analysis of the data corresponding to the degree of disability at the moment of diagnosis, as shown in Graph 4, the present study reveals that, regarding grade I, 2009 stood out with 33.6% and 2011 with 27.8% of cases. found. As for grade II, there was also a significant increase upon diagnosis of the disease, where 2009 presented 16.8% and 2011 with 13.2%, when compared to other years. Such analysis can be observed in the following graph:



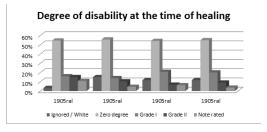
Graph 4: assessment of degree of disability at diagnosis

Graph 4 shows that the proportion of grade I and II disabilities increased significantly in 2009 and 2010. The presence of these disabilities at the time of disease detection is probably associated with late diagnosis.5

According to epidemiological indicators proposed by the Ministry of Health, the proportion of grade II disability in patients with high medication in 2009 (15.1%) and 2010 (10.5%) is considered high (greater than or equal to 10%). Already in 2011 (6.9%) and 2012 (9.2%) is considered average (5% to 9.9%). This means that there was an improvement in the epidemiological indicator, and in the health service.

Research has shown the effectiveness of treatment with multidrug therapy, with a decrease in the rate of deformities among new cases. This treatment protocol has enabled early diagnosis and systematic follow-up, associated with neural monitoring and interventions for proper diagnosis and treatment of neuropathy episodes associated or not with reactionary conditions (GONÇALVES; SAMPAIO; ANTUNES, 2009).

Early diagnosis and specific therapy for each reaction state are of great importance for the prevention of disabilities, which are due to the immunoinflammatory process in peripheral nerves, mainly of the hands, feet and eyes (ANTONIO et al., 2011).



Graph 5: Evaluation of the degree of disability at the time of cure

Regarding the degree of disability at the time of cure, it can be seen in graph 5, that in relation to grade I and grade II, there was a decrease in the number of cases with physical disabilities between 2009 and 2012. This confirms that the diagnosis was made early and the treatment instituted efficiently, since, in general, the evolution of these degrees was satisfactory for the entire sample, probably due to a possible improvement in the services of the health units, teams of professionals trained to perform the attendance of new cases, diagnosing the disease when it was still in its beginning, besides the expansion of the sanitary dermatology service of the place studied after 2009.

The fact of improvement or worsening or maintenance of the patient's clinical condition after drug treatment is associated or reflects its initial condition. This aspect is important in rehabilitation, as the focus of treatment is not only to cure the disease, but also to develop patients' functional capacity to the maximum and prevent new disabilities from occurring

### (GONÇALVES; SAMPAIO; ANTUNES, 2009).

In 2010, 2011 and 2012, there was a high number of patients whose grade was ignored at the time of cure compared to 2009, unlike the time of diagnosis, where no case was ignored. In addition, there was a considerable increase in the number of individuals who were not evaluated at the time of cure in relation to the time of diagnosis, as can be seen in graph 5.

### **FINAL CONSIDERATIONS**

Leprosy is the main cause of disability among infectious diseases, should be prevented and treated early, in order to prevent the emergence of deformities that generate physical disabilities. Thus, it is important to prevent disabilities, following from the early diagnosis of the disease to its treatment, thus preventing the installation of deformities, and consequently reducing the stigma and prejudice caused by it. Therefore, the need for increased early detection actions and effective prevention of this disease is fundamental.

Regarding the characterization of the sample, it was evident that the male gender was the most prevalent among the forms investigated, with priority age for economically active patients (15-59 years). It is also important to highlight that the tuberculoid form was the most incident and the municipality of João Pessoa had a higher number of disabilities. The present study showed that most of the affected individuals were evaluated at the moment of diagnosis and at the time of cure, with a predominance of grade zero in both moments.

Thus, it is hoped that this study will enable further reflection and further investigation on the evaluation of the degree of disability in leprosy patients, with the aim of improving the care provided to such individuals.

#### REFERENCES

PUCCI, F.H. et al. Ador no paciente com hanseníase. Rev. Dor. jan-mar; 12(1):15-18, 2011.

BRASIL. Ministério da Saúde. Secretaria de Políticas de Saúde. Departamento de Atenção Básica. Guia para o Controle da hanseníase. Brasília: Ministério da Saúde, 2002.

RAMOS, J. M. H.; SOUTO, F. J. D. Incapacidade pós-tratamento em pacientes hansenianos em Várzea Grande, Estado de Mato Grosso. RevSocBrasMed Trop. mai-jun; 43(3):293-297, 2010.

MARTINS, B. D. L. et al. Impacto na qualidade de vida em pacientes com hanseníase: correlação do Dermatology Life Quality Index com diversas variáveis relacionadas à doença. An. Bras. Dermatol.; 83(1):39-43, 2008.

RODINI, F. C. B. et al. Prevenção de incapacidades na hanseníase com apoio em um manual de autocuidado para pacientes. FisioterPesqui. abr-jun; 17(2):157-166. 2010.

ALVES, C. J. M. et al. Avaliação do grau de incapacidade dos pacientes com diagnóstico de hanseníase em Serviço de Dermatologia do Estado de São Paulo. Rev. Soc. Bras. Med. Trop. jul-ago; 43(4):460-461, 2010.

GONÇALVES, S.D. et al. Fatores preditivos de incapacidades em pacientes com hanseníase. Rev. Saúde Pública; 43(2):267-274, 2009.

BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância Epidemiológica. Hanseníase no Brasil: dados e indicadores selecionados. 1 ed. Brasília, Ministério da Saúde, 2009.

RIBEIRO, F. S. et al. Qualidade dos serviços prestados pelos centros de saúde da família de Sobral – Ceará aos portadores de hanseníase nos anos de 2009 e 2010. SANARE. jul-dez; 11(2):44-51, 2012.

NARDI, S. M. T. et al. Frequência de avaliações e seu impacto na prevenção das incapacidades físicas durante os tratamentos dos pacientes com hanseníase. Hansen. Int. jul-dez; 30(2):157-166, 2005.

SILVA, S. R.A. et al. Avaliação do grau de incapacidade em hanseníase:uma estratégia para sensibilização e capacitação da equipe de enfermagem. Rev. Latino-Am. Enfermagem [online]. nov-dez; 15(6), 2007.

BEZERRA, F. N. et al. Impact of the diagnosis of leprosy. RevEnferm UFPE online. dez; 5(spe):2624-2634, 2011.

MIRANZI, S. S. C. et al. Perfil epidemiológico da hanseníase em um município brasileiro, no período de 2000 a 2006. RevSocBras Trop. jan-fev; 43(1):62-67, 2010.

MELÃO S. et al. Perfil epidemiológico dos pacientes com hanseníase no extremo sul de Santa Catarina, no período de 2001 a 2007. Rev. SocBrasMed Trop. jan-fev; 44(1):79-84, 2011.

SOUZA, V. F. M. et al. Relato de três casos novos de hanseníase em menores de quinze anos no município de Itaguaí, Rio de Janeiro: evento de alerta para investigação epidemiológica. AnBrasDermatol. out; 86(5):1011-1015, 2011.

SOARES, F. N. et al. Caracterização dos participantes de um programa de prevenção de incapacidades para hanseníase. Rev enferm UFPE on line. fev; 7(2):491-496, 2013.

BRASIL. Ministério da Saúde (MS). Vigilância em Saúde situação epidemiológica da hanseníase no Brasil [site na Internet]. Brasília: Programa Nacional de Controle de Hanseníase. [acessado 2010 ago 13]. Disponível em: http://portal.saude.gov.br/portal/arquivos/pdf/boletim\_novembro.pdf.

ANTONIO, J. R. et al. Avaliação epidemiológica dos estados reacionais e incapacidades físicas em pacientes com hanseníase na cidade de São José do Rio Preto. Arq. Cienc Saúde. jan-mar; 18(1):9-14, 2011.

# EVALUATION OF THE DISABILITY DEGREE OF PATIENTS WITH A DIAGNOSIS OF LEPROSY

Leprosy causes great damage to daily life and interpersonal relationships, causing suffering that goes beyond pain and discomfort strictly linked to physical impairment, with great social and psychological impact. The involvement of peripheral nerves is the main characteristic of leprosy, giving it a great potential to cause physical disabilities that may even develop into deformities. The objective of this study was to evaluate the degree of disability of leprosy patients based on the database of the Notification Disease Information System. It is a descriptive, observational and retrospective study. The population consisted of all leprosy patients notified by the local Epidemiological Surveillance. The sample consisted of 458 service notification forms from 2009 to 2012. The collection was performed by the Tabwin32 program, and the results were displayed in graphs and tables. Results: Most of the evaluated cases had zero disability degree in both evaluation moments, there was a decrease in the number of cases evaluated as grade I and II when compared at the time of diagnosis and cure. The most commonly observed clinical form was tuberculoid. Conclusion: The results of this work reinforce the relevance of developing health education actions so that there is early detection and proper management of identified cases. Keywords: Leprosy; Epidemiology; Public health.

Keywords: Leprosy; disabilities; patient.

## EVALUATION DE L'INVALIDITE DES PATIENTS ATTEINTS DE DIAGNOSTIC DE L'HANSENIASE

La lèpre porte gravement atteinte à la vie quotidienne et aux relations interpersonnelles, provoquant des souffrances qui vont au-delà de la douleur et de l'inconfort strictement liés à une déficience physique, avec un impact social et psychologique important. L'atteinte des nerfs périphériques est la principale caractéristique de la lèpre, ce qui lui confère un grand potentiel de

causer des handicaps physiques pouvant même déboucher sur des malformations. L'objectif de cette étude était d'évaluer le degré d'invalidité des patients atteints de lèpre à partir de la base de données du système d'information sur les maladies. C'est une étude descriptive, observationnelle et rétrospective. La population était composée de tous les patients atteints de lèpre notifiés par la surveillance épidémiologique locale. L'échantillon comprenait 458 formulaires de notification de service de 2009 à 2012. La collecte a été effectuée par le programme Tabwin32 et les résultats ont été affichés sous forme de graphiques et de tableaux. Résultats: La plupart des cas évalués ne présentaient aucun degré d'invalidité aux deux moments de l'évaluation, mais le nombre de cas évalués en grades I et II a diminué par rapport au moment du diagnostic et de la guérison. La forme clinique la plus fréquemment observée était tuberculoïde. Conclusion: Les résultats de ces travaux renforcent la pertinence de développer des actions d'éducation pour la santé afin de permettre une détection précoce et une gestion appropriée des cas identifiés. Motsclés: lèpre; Épidémiologie; Santé publique.

Mots-clés: lèpre; les handicaps; patient.

# EVALUACIÓN DE LA DISCAPACIDAD DE PACIENTES CON DIAGNÓSTICO DE HANSENIASIS

La lepra causa un gran daño a la vida cotidiana y a las relaciones interpersonales, causando un sufrimiento que va más allá del dolor y la incomodidad estrictamente relacionados con el deterioro físico, con un gran impacto social y psicológico. La participación de los nervios periféricos es la característica principal de la lepra, ya que le brinda un gran potencial para causar discapacidades físicas que incluso pueden convertirse en deformidades. El objetivo de este estudio fue evaluar el grado de discapacidad de los pacientes con lepra con base en la base de datos del Sistema de Información de Enfermedades de Notificación. Es un estudio descriptivo, observacional y retrospectivo. La población consistió en todos los pacientes con lepra notificados por la Vigilancia Epidemiológica local. La muestra consistió en 458 formularios de notificación de servicio de 2009 a 2012. La recolección fue realizada por el programa Tabwin32, y los resultados se mostraron en gráficos y tablas. Resultados: la mayoría de los casos evaluados tenían un grado de discapacidad cero en ambos momentos de evaluación, hubo una disminución en el número de casos evaluados como grado I y II en comparación con el momento del diagnóstico y la cura. La forma clínica más comúnmente observada fue tuberculoide. Conclusión: Los resultados de este trabajo refuerzan la relevancia del desarrollo de acciones de educación en salud para que haya una detección temprana y un manejo adecuado de los casos identificados. Palabras llave: lepra; Epidemiología Salud pública.

Palabras llave: lepra; discapacidades; paciente

# AVALIAÇÃO DO GRAU DE INCAPACIDADE DOS PACIENTES COM DIAGNÓSTICO DE HANSENÍASE

A hanseníase causa grande prejuízo para a vida diária e as relações interpessoais, provocando sofrimento que ultrapassa a dor e o mal-estar estritamente vinculados ao prejuízo físico, com grande impacto social e psicológico. O comprometimento dos nervos periféricos é a característica principal da hanseníase, dando-lhe um grande potencial para provocar incapacidades físicas que podem, inclusive, evoluir para deformidades. Objetivou-se nesse trabalho avaliar o grau de incapacidade dos pacientes de hanseníase com base no banco de dados do Sistema de Informação de Agravos de Notificação. Trata-se de um estudo descritivo, observacional e restrospectivo. A população foi composta por todos os pacientes de hanseníase notificados pela Vigilância Epidemiológica do local. A amostra foi constituída por 458 fichas de notificação do serviço no período de 2009 a 2012. A coleta foi realizada pelo programa Tabwin32, e os resultados foram expostos em gráficos e tabelas. Resultados: A maioria dos casos avaliados teve grau de incapacidade zero nos dois momentos de avaliação, houve diminuição dos números de casos avaliados como grau I e II quando comparados no momento do diagnóstico e da cura. A forma clínica mais observada foi a tuberculóide. Conclusão: Os resultados deste trabalho reforçam a relevância de se desenvolver ações de educação em saúde para que haja uma detecção precoce e manejo adequado dos casos identificados. Descritores: Hanseníase; Epidemiologia; Saúde Pública.

Descritores: Hanseniase; incapacidades; paciente.