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POST-DISCHARGE OF SUBJECTS WITH LEPROSY: PREVALENCE OF PHYSICAL DISABILITIES AND OVERLAPPING OF OTHER DISEASES

Érica Juliana Benício Araújo¹, Olívia Dias de Araújo², Telma Maria Evangelista de Araújo³, Priscilla Dantas Almeida⁴, Inara Viviane de Oliveira Sena⁵, Érica de Alencar Rodrigues Neri⁵

ABSTRACT: Objective: To characterize the prevalence of physical disabilities in individuals affected by post-discharge leprosy and its relationship with chronic diseases. Method: The study population consisted of 603 new cases of leprosy reported between 2001 and 2014 in endemic municipalities in the state of Piauí. Data was collected through questionnaires and simplified neurological evaluation. Statistical analyzes were performed by frequency distribution, Pearson's Chi-square test and Fisher's Exact test. Results. The prevalence of physical disability was 70.43%, and there was a significant association with the multibacillary clinical form, male gender, old age and low educational level (p <0.01). Conclusion: Overlapping of diseases was not a risk factor for the development of physical disabilities, but there was a higher frequency of diabetic and hypertensive subjects in the group with physical disabilities. It is necessary to plan health actions that are more suitable to the population, strengthening the longitudinality of care to chronic conditions.

DESCRIPTORS: Leprosy; Disabled people; Epidemiology; Chronic disease; Public health.

PÓS-ALTA DE HANSENÍASE: PREVALÊNCIA DE INCAPACIDADES FÍSICAS E SOBREPOSIÇÃO DE DOENÇAS

RESUMO: Objetivo: caracterizar a prevalência de incapacidades físicas em indivíduos acometidos por hanseníase no pós-alta e sua relação com as doenças crônicas. Método: a população da pesquisa foi de 603 casos novos de hanseníase notificados entre 2001 e 2014 em municípios endêmicos no Piauí. Os dados foram coletados mediante aplicação de questionários e avaliação neurológica simplificada. Análises estatísticas foram realizadas por distribuição de frequência, testes Qui-quadrado de Pearson e Exato de Fisher. Resultados: observou-se a prevalência de incapacidade física de 70,43%, e associação significativa com a forma clínica multibacilar, sexo masculino, idade avançada e baixa escolaridade (p<0,01). Conclusão: a sobreposição de doenças não se comportou como um fator de risco, mas constatou-se frequência importante de pessoas. Registra-se a necessidade de planejamento de ações de saúde mais adequadas à população, fortalecendo a longitudinalidade do cuidado frente às condições crônicas.

DESCRITORES: Hanseníase; Pessoas com deficiência; Epidemiologia; Doença crônica; Saúde pública.

POST-ALTA DE LEPRA: PREVALENCIA DE DISCAPACIDADES FÍSICAS Y SUPERPOSICIÓN DE ENFERMEDADES

RESUMEN: Objetivo: Caracterizar la prevalencia de discapacidades físicas en individuos afectados por lepra luego del alta y su relación con las enfermedades crónicas. Método: La población del estudio fue de 603 casos nuevos de lepra notificados entre 2001 y 2014 en municipios endémicos de Piauí. Datos recolectados mediante aplicación de cuestionarios y evaluación neurológica simplificada. Se realizaron análisis estadísticos de distribución de frecuencia, tests de Chi-cuadrado de Pearson y Exacto de Fisher. Resultados: Se observó prevalencia de discapacidad física del 70,43%, y asociación significativa con la forma clínica multibacilar, sexo masculino, edad avanzada y baja escolarización (p<0,01). Conclusión: La superposición de enfermedades no constituyó un factor de riesgo, aunque se la constató en importante cantidad de personas. Se registra la necesidad de planificación de acciones de salud más adecuadas a la población, fortaleciendo la atención longitudinal frente a las condiciones crónicas.

DESCRIPTORES: Lepra; Personas con Discapacidad; Epidemiología; Enfermedad Crónica; Salud Pública.

Corresponding author:

Priscilla Dantas Almeida Universidade Federal do Piauí Av. Frei Serafim, 2280 - 64000-020 - Teresina, PI, Brasil E-mail: priscilladant@hotmail.com Received: 23/02/2018

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¹Nurse. Universidade Federal do Piauí. Teresina, PI, Brazil.

²Nurse. PhD in Nursing. Professor of Nursing from Universidade Federal do Piauí. Teresina, PI, Brazil.

³Nurse. PhD in Collective Health Nursing. Professor of Nursing from Universidade Federal do Piauí. Teresina, PI, Brazil.

⁴Nurse. MSc in Health and Community. Universidade Federal do Piauí. Teresina, PI, Brazil.

⁵Nurse. MSc in Nursing. Universidade Federal do Piauí. Teresina, PI, Brazil.

INTRODUCTION

Leprosy remains an important public health problem in Brazil due to the extent of its physical and socioeconomic consequences, as well as to the endemicity of some Brazilian states (1).

The disease manifests itself by dermatoneurological disorders, such as infections affecting the skin and the peripheral nervous system. It causes damage to the eyes, hands, and feet, generating motor and sensory disorders with significant physical, social and economic impacts⁽²⁾.

According to the World Health Organization (WHO), in 2016, new cases of leprosy were recorded in 14 endemic countries; 143 countries reported 214,783 new cases of leprosy, which represents a detection rate of 2.9 cases per 100 thousand inhabitants. Brazil is classified as high disease burden, ranking second in the world in the number of new cases of leprosy recorded⁽³⁾.

Despite the significant reduction in the number of new cases of leprosy in the last 10 years, detection rates are still high in Brazil, with a non-uniform distribution of cases and concentration in hyperendemic areas, mainly in the North, Center-West and Northeast regions. In 2014, 31,064 new cases were recorded in Brazil, with a general detection rate of 15.32 per 100,000 inhabitants. In Piauí, despite the significant reduction in the prevalence rate of leprosy, which in 2014 was 2.49 cases/10 thousand inhabitants, the state still requires more effective actions to overcome the disease⁽⁴⁾.

The percentage of patients detected with physical disabilities and evidence of delayed diagnosis and neural impairment corroborates this situation. About 20% of the individuals affected by leprosy may have disabilities or psychosocial problems, needing some kind of support and/or rehabilitation. In Brazil, 6.6% of the new cases detected in the diagnosis had an impairment grading of grade 2. In Piauí, the percentage is 5.7%. Therefore, in addition to the chemotherapy treatment, it is necessary to emphasize the importance of techniques of prevention, control and treatment of the disabilities and deformities, such as integral care to individuals with leprosy (3,5-6).

In the context of public health transitions, leprosy represents a chronic health condition that affects children and adults, with great potential to be associated with other chronic and degenerative conditions, maximizing them or modifying their natural history. Therefore, leprosy increases, in vulnerable and neglected populations, not only its specific disease burden, but also the burden of other diseases, posing major challenges to the health systems of endemic countries. Because of the social context of leprosy and the fact that this condition continues to be neglected, individuals affected by other diseases in the post-discharge period are not continuously monitored⁽⁷⁾.

Leprosy's behavior related to other coexisting chronic diseases such as diabetes and arterial hypertension is still little known. However, the impact of the relationship between leprosy and chronic diseases regarding the investigation of an incapacitating potential of leprosy associated with these diseases is perceived.

Since leprosy is a public health problem in Brazil and in the state of Piauí, the various aspects that may be associated with the development of physical disabilities and the need to identify whether or not there is a relationship between the association of chronic diseases and leprosy and the worsening of this condition, the present study aimed to characterize the prevalence of physical disabilities in subjects cured of leprosy in the post-discharge and its relationship with overlapping of chronic diseases.

METHOD

This study is part of a macroproject of the Graduate Program in Nursing of Universidade Federal do Piauí (UFPI) called "INTEGRAHANS PIAUÍ: an integrated approach to the clinical, epidemiological, operational and psychosocial aspects of leprosy in highly endemic municipalities in the state of Piauí."

Cross-sectional study conducted in two municipalities of Piauí with high endemicity of leprosy: Floriano (cluster 1), considered a hyperendemic municipality, with a population of 58,803 thousand people and a territorial area of 3,409,649 km², and Picos (cluster 6), an endemic municipality, with a population of 73,414 thousand inhabitants and a territorial area of 577,304 km².

The definition of the study population was based on the consolidation of data from the SINAN (a national system of information on notifiable diseases and events) regarding new cases notified in Floriano and Picos from 2001 to 2014, totaling 1765 cases.

Of the total number of cases, 751 (42.45%) were not detected. Of the 1,014 (57.45%) cases detected, 321 (31.66%) were not treated because of the following reasons: change of address, death or because the individuals were not at home when the Community Health Worker Agent arrived. Of the total study population, 90 (12.99%) individuals did not agree to participate in the study.

Thus, 603 subjects participated in the study, and of these, 311 (51.58%) were from Floriano and 292 (48.42%) from Picos. The inclusion criterion selected was as follows: participants in post-discharge for cure of leprosy who have been diagnosed and treated in the referred municipalities. The subjects who moved to another municipality were excluded.

Data was collected from July 2015 to June 2016. The mapping of cases and confirmation of the addresses of the individuals were performed by comparing SINAN's data with the addresses contained in the User Registration Information System of the SUS (CADSUS) and the deaths, with the Mortality Information System (SIM). After the identification of the households, the multidisciplinary team of home care visited the individuals with leprosy and invited them to participate in the study at previously established places and dates, and all the objectives and procedures were duly explained.

Data was collected in standardized interviews, through the administration of structured questionnaires, and clinical examination of the patients by the professionals involved in the project and previously trained collaborators. The subjects who missed the scheduled appointments were visited in their homes by the multidisciplinary team of home care. The teams made three visits to the participants, and made phone calls, when possible, to reinforce the invitation.

The highest physical disability grade (GIF) identified in the Simplified Neurological Evaluation recommended by the Ministry of Health allowed the assessment of the magnitude of the disabilities. Determination of disability grades was based on simplified neurological evaluation of the eyes, hands and feet, and the result was expressed in values ranging from 0 (zero) to 2 (two), as follows: 0 - absence of neural involvement; 1 - decrease or loss of sensitivity; 2 - presence of visible disabilities and deformities $^{(6,8)}$.

Socioeconomic and clinical variables such as gender, age, education, occupation, marital status, operational classification, clinical form, eyes, hands and feet score (EHF) score, occurrence of leprosy reactions, general clinical profile data such as the presence of chronic diseases (diabetes and hypertension) and other comorbidities, and data related to the service, such as the frequency of visits of the Community Health Agent (ACS) during and after MDT (multi-drug therapy)and the simplified neurological evaluation.

The data were entered and stored in Epi-Info version 7.1.5.0 software and analyzed with the use of Stata 13.0 software. For the analysis, in addition to descriptive approach, Pearson's Chi-square test and Fisher's exact test were used, with a 95% confidence level and a significance level of 5%.

The study was approved by the Research Ethics Committee of UFPI, under Protocol no 1,115,818.

RESULTS

The prevalence of the Physical Disability Grade (GIF) was identified in the subjects examined (70.43%, n = 424) and the results were as follows: GIF 1 (54.32%, n = 327) and GIF 2 (16.11% n = 97).

The study sample was mostly composed of women (52.07%, n = 314), with a mean age of 51.6 years, ranging from 10 to 102 years old, with a predominance of elderly subjects(36.49%, n = 216), married or living with a companion (50.68%, n = 300), incomplete primary education (46.06%, n = 269) and who have declared themselves as brown or black (72.48%, n = 424).

There was a higher percentage of paucibacillary cases (53.57%, n = 323) and the predominant clinical form was indeterminate (36.36%, n = 216), followed by borderline (28.62%, n = 170). Regarding the

occurrence of leprosy reactions, 22.18% (n = 122) had a reaction episode.

Physical disability was more frequent in males over 60 years old, and disabilities were more common in older individuals (p <0.01). The mean age of the subjects with physical disability was 55.11 years. Separated, divorced or widowed individuals were more disabled (p <0.01), as well as illiterate individuals (p <0.01). The association with self-reported skin color was not statistically significant (Table 1).

Table 1 – Clinical and sociodemographic characterization of cases of leprosy according to the presence of physical disability. Floriano and Picos, PI, 2017

N % n % N Operational classification ^a Paucibacillary 128 39.63 195 60.37 323 Multibacillary 50 17.92 229 82.08 279 Clinical form ^b Indeterminate 117 92.13 10 7.87 127 Tuberculoid 55 8730 8 12.70 63 Borderline 88 75.86 28 24.14 116 Virchowian 25 41.67 35 58.33 60 Leprosy reactions ^{a(1)} 107 207 60.04 432	p value
Paucibacillary 128 39.63 195 60.37 323 Multibacillary 50 17.92 229 82.08 279 Clinical formb Indeterminate 117 92.13 10 7.87 127 Tuberculoid 55 8730 8 12.70 63 Borderline 88 75.86 28 24.14 116 Virchowian 25 41.67 35 58.33 60 Leprosy reactionsa(1) 	-
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Borderline 88 75.86 28 24.14 116 Virchowian 25 41.67 35 58.33 60 Leprosy reactions ^{a(1)}	
Virchowian 25 41.67 35 58.33 60 Leprosy reactions ^{a(1)}	0.00
Leprosy reactions ^{a(1)}	0.00
N- 427 20.00 20F 60.04 422	
No 127 30.09 295 69.91 422	0.42
Yes 32 26.45 89 73.55 121	0.43
Gendera	
Male 68 23.61 220 76.39 288	
Female 110 35.03 204 64.97 314	0.00
Age range ^b	
< 15 years 5 62.50 3 37.50 8	
15- 29 years 40 54.05 34 45.95 74	
30-44 years 47 40.87 68 59.13 115	0.00
45-59 years 46 27.22 123 72.78 169	
≥ 60 years 33 15.49 180 84.51 213	
Marital status ^b	
Single 59 37.34 99 62.66 158	
Married/in a stable relationship 89 30.07 207 69.93 296	0.00
Separated/Divorced/Widowed 23 18.40 102 81.60 125	
Education ^b	
Illiterate 17 14.66 99 85.34 116	
Complete Primary education 12 34.29 23 65.71 35	· · 0.00
Incomplete Primary Education 64 24.33 199 75.67 263	
Complete Secondary Education 45 49.45 46 50.55 91	
Incomplete Secondary Education 16 37.21 27 62.79 43	
Complete Higher Education 15 65.22 8 34.78 23	
Skin color (self-reported) ^b	
White 26 27.66 68 72.34 94	
Brown/Black 122 29.61 290 70.39 412	0.85
Other 21 31.82 45 68.18 46	

^(a)Pearson's chi-square test; ^(b) Fisher's exact test; ⁽¹⁾ 60 people did not know or did not want to talk about the occurrence of leprosy reactions.

The frequency of physical disability was higher in multibacillary cases and in the Virchowian clinical form (p <0.01). The mean EHF scores in physical disability was 2.87. No statistical significance was found in the association with leprosy reactions. However, of the subjects who had reactive episodes, most (73.55%, n = 121) had some degree of physical impairment in the post-discharge of leprosy (Table 1).

Regarding follow-up by health care services, 77.74% (n = 248) of the subjects said they have been visited at home by a Community Health Agent (CHA) during MDT and that they had physical disability (p <0.01). During treatment, 77.61% (n = 430) subjects were assessed through the simplified neurological evaluation (Table 2).

Table 2 – Care delivered by health services during and after MDT according to the presence of physical disabilities. Floriano and Picos, PI,2017

Variables	Without physical disability		With physical disability		TOTAL	p value
	n	%	n	%	N^1	
Visited at home by a CHA during MTD						
No	0	35.29	143	64.71	221	0.00
Yes	71	22.26	248	77.74	319	
Visited at home by a CHA in post MTD ^a						
No	84	34.57	159	65.43	243	0.00
Yes	74	24.26	231	75.74	305	
Assessed (ANS) ^a						
No	31	25	93	75	124	0.27
Yes	129	30	301	70	430	

⁽a) Pearson's chi-square test; (b) Fisher's exact test; (1) The total values (n) may differ as a result of missing data.

The diseases most frequently identified in the subjects were diabetes (12.03%, n=71) and hypertension (24.45%, n=145). Significant results were obtained only in the association with hypertension (p < 0.01), and of the total number of subjects diagnosed with leprosy, 80% (n=116) had a physical disability at the time of the assessment.

Table 3 – Distribution of chronic non-communicable diseases in post-discharge of leprosy regarding the presence of physical disabilities. Floriano and Picos, PI, Brazil, 2017 (continues)

Variables	Without physical disability		With physical disability		Total	p value
	n	%	n	%	N ⁽¹⁾	
Diabetes ^a						
No	158	30.86	354	69.14	512	
Yes	16	22.54	55	77.46	71	0.15
Hypertension ^a						
No	144	32.65	297	67.35	441	
Yes	29	20	116	80	145	0.001
Other comorbidities ^b						
CVA	0	0.00	6	100	6	
Arthrosis	3	21.43	11	78.57	14	
Depression	1	20	4	80	5	

Herniated disc	1	25	3	75	4	
Osteoporosis	1	10	9	90	0	
Others	28	30.43	64	69.57	92	0.54

⁽a) Pearson's chi-square test; (b) Fisher's exact test; (1). The total values (n) may differ as a result of missing data.

DISCUSSION

The presence of disabilities and deformities caused by leprosy in a post-discharge patient is an indication that the diagnosis was late or clinical follow-up was inadequate, indicating that post-discharge care is very challenging and complex(9). The occurrence of GIF can indirectly measure the magnitude of leprosy, since most patients do not develop deformities in the early stages of the disease (10). There was a high prevalence of physical disability in this study, and it was higher than the literature findings(7,11). The number of subjects with GIF 1 was higher than those with GIF 2, which is consistent with official data and previous studies (1,8,12).

Most leprosy patients were women, which is consistent with studies with patients attending a leprosy eradication program in São Luís-MA and a University Hospital of Ceará (12-13). It was suggested that the greater concern with body aesthetics and the specific policies for the female population could justify the predominance of women in the sample (12). Regarding age, according to the Ministry of Health, leprosy mainly affects the economically active population, ranging from 20 to 60 years (6). The mean age observed in this study was higher than that found in the literature in similar studies with a population in the post-discharge period (8,10-11) demonstrating that the subjects with leprosy in the municipalities where the study was conducted were older.

The predominance of individuals with low or no education at all reaffirms that a low educational attainment is an important risk factor for health. It is a strong indicator of poor housing, nutrition, hygiene and access to health services, which are key factors for the maintenance of the leprosy transmission chain. This situation may increase the vulnerability of these individuals, which may make it difficult to understand, adopt treatment and self-care measures (8,14-16).

The higher frequency of paucibacillary cases and indeterminate clinical form was similar to the results reported in the literature, reinforcing the importance of timely and adequate diagnosis by health services, based on actions targeted to leprosy control. Important factors that optimize the diagnosis include proper access to care, communication and health education (17).

Approximately 25-30% of the patients with leprosy develop leprosy reactions or neural damage at some point in their lives. Depending on the function of the nerve, when it is normal, 16% of people may have a reaction; on the other hand, if abnormalities are detected in the nerve, this rate may increase to 65% ⁽⁷⁾. The percentage of occurrence of reactive episodes decreases as the elapsed time after completion of MDT increases ⁽¹⁵⁾, which may explain the lower percentages obtained for these parameters in the present study, where the population was in the post-discharge by cure of leprosy. This fact, however, does not exclude the importance of maximizing specific and multidisciplinary care to this clinical event, since leprosy reactionsmay cause serious complications.

The estimated prevalence of physical disability was higher in men than in women, as seen in studies^(11-12,15), possibly indicating a later detection of these conditions among this population, as men usually access primary health care services only to treat a specific morbidity⁽¹⁸⁾. The result of the present study was similar to another study⁽¹⁰⁾ that reported a relationship between aging and the presence of GIF in its analysis of physical disability, grade and age, as follows: subjects with GIF 0 had a mean age of 34 years; subjects with GIF 1 had a mean age of 49 years, and subjects with GIF 2 had a mean age of 57 years. The diagnosis performed in older patients may indicate disease chronicity and possible onset of neural damage.

There was a significant relationship between the onset of disabilities and lower educational level. It is through health education that people are sensitized about the first signs of leprosy, the need for early

diagnosis and prevention of disabilities. Various community spaces can be used to disseminate such information, such as group meetings, waiting rooms, advertisements (19). Individuals who have difficulty in complying with the guidelines for treatment, prevention of disabilities and self-care measures are more likely to develop complications or deformities, or to experience a worsening of these conditions.

The presence of some degree of impairment was more frequent in individuals who had the Virchowian and Borderline clinical forms compared to those with paucibacillary forms (indeterminate and tuberculoid). Multibacillary patients were 5.7 times more likely to develop disability than paucibacillary patients. One explanation for this result is that multibacillary cases are diagnosed later, which may lead to the onset of delayed diagnosis-related disabilities (11,20).

Many subjects said they did not receive the simplified neurological evaluation. This is not consistent with the recommendation of the Ministry of Health (6) and makes it impossible to monitor de subjects and provide high quality care to individuals with leprosy.

Regarding disease overlapping, the findings of the present study were similar to those of a study carried out in São José do Rio Preto-SP, in 2012, where the frequently associated diseases were diabetes and arterial hypertension ⁽⁸⁾. In the referred study, there was not a statistically significant difference between the subjects who had physical disabilities and those who had some associated disease. Comorbidity was not a risk factor for the development of physical disabilities, but there was a higher frequency of diabetic and hypertensive subjects in the group with physical disabilities compared to the group of subjects who had no disability.

The slow infectious process associated with leprosy, low lethality and the occurrence of immunological events favor the increase of morbimortality in populations affected when associated with other diseases. Issues such as isolation, stigma, restriction of social interaction, functional limitation, and physical disability not only increase the challenges for managing leprosy as a chronic condition but also the frequency and magnitude of risk factors for other chronic noncommunicable diseases (CNCD) (17).

The large number of people currently affected by these diseases, especially the elderly, the prevalent age group in this study, also deserves mention. According to the National Health Survey conducted by the Ministry of Health in partnership with the Brazilian Institute of Geography and Statistics (IBGE), about 40% of the Brazilian adult population, approximately 57.4 million people, has at least one CNCD. The most common are hypertension and diabetes, which affect 21.4% and 6.2% of the population, respectively.

Diagnosis of leprosy in Brazil is still delayed, even after the first symptoms. The Ministry of Health and other organizations carry out projects and campaigns to highlight the need for early identification of the signs and symptoms of the disease, as well as to promote the implementation of proper and effective procedures for disease control and quality of life⁽⁷⁾.

One limitation of the study concerns the incompleteness of data and inconsistency of information provided by the SINAN database, which made it difficult to contact the subjects with leprosy. This problem was solved by crossing such data with CADSUS and SIM databases. Further studies based on this system are recommended, as they will allow reliable assessments of the epidemiological situation of health conditions.

CONCLUSION

The overlapping of diseases was not a risk factor for the onset of physical disabilities, but a significant percentage of individuals were affected by diseases that caused some degree of impairment.

The study revealed alarming data on the situation of people in the post-discharge of the leprosy in the evaluated municipalities, which leads to reflect on the quality of the actions and services provided by the health units regarding care to individuals with leprosy. Knowledge of the post-discharge status of people affected by leprosy makes it possible to plan health actions more suitable to this population through the early identification of situations of vulnerability.

Training for primary care professionals (doctors, nurses, dentists and community health agents) is recommended, as well as for professionals in the secondary and tertiary levels who may participate in the post-discharge process of these patients, for the prevention and treatment of physical disabilities resulting from leprosy. It is also important to build a care model, focused on the healthcare network, to strengthen the longitudinality of care.

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