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SOCIOECONOMIC AND DEMOGRAPHIC PROFILE OF LEPROSY CARRIERS ATTENDED IN NURSING CONSULTATIONS

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Leprosy is a contagious infectious disease that manifests due to unfavorable socioeconomic factors, endemic levels and individual conditions. This study aimed to recognize the socioeconomic and demographic profile and degree of incapacity installed in leprosy carriers attended at the School Health Center in Botucatu. Data were obtained through nursing consultation performed in 37 patients. The results showed a predominance of individuals with stable union (78%), whites (92%), age between 30 and 49 years old (51%), low level of schooling (68% with incomplete primary education) and those with per capita familial income less than one minimum salary (59 %). More than one third of the patients investigated (35%) presented some degree of physical incapacity. The association of low socioeconomic profile with the presence of physical incapacities assigns greater vulnerability to this population and can negatively influence their quality of life.

DESCRIPTORS: leprosy; socioeconomic factors; residence characteristics; disabled persons

PERFIL SOCIOECONÓMICO Y DEMOGRÁFICO DE PORTADORES DE LEPRA ATENDIDOS EN CONSULTA DE ENFERMERÍA

La lepra es una enfermedad infecto-contagiosa que se manifiesta debido a factores socioeconómicos desfavorables, niveles de endemia y condiciones individuales. El objetivo de este estudio fue reconocer el perfil socioeconómico y demográfico y el grado de incapacidad instalado de los portadores de lepra atendidos en el Centro de Salud Escuela de Botucatu. Los datos fueron obtenidos a través de consulta de enfermería realizada en 37 pacientes. Los resultados mostraron una predominancia de individuos con unión estable (97,8%), blancos (92%), con edad entre 30 y 49 años (51%), con bajo nivel de escolaridad (68 % con enseñanza primaria incompleta) y con renta familiar per capita menor que un salario mínimo (59 %). Más de un tercio de los pacientes investigados (35%) presentaban algún grado de incapacidad física. La asociación del bajo perfil socioeconómico con la presencia de incapacidades físicas imprime mayor vulnerabilidad a esa población, lo que puede influenciar negativamente su calidad de vida.

DESCRIPTORES: lepra; factores socioeconómicos; distribuición espacial de la población; personas con discapacidad

PERFIL SOCIOECONÔMICO E DEMOGRÁFICO DE PORTADORES DE HANSENÍASE ATENDIDOS EM CONSULTA DE ENFERMAGEM

A hanseníase é doença infecto-contagiosa para a qual, além das condições individuais, outros fatores relacionados aos níveis de endemia e às condições socioeconômicas desfavoráveis influem no risco de adoecer. Objetivou-se reconhecer o perfil socioeconômico e demográfico e o grau de incapacidade instalado dos portadores de hanseníase, atendidos no Centro de Saúde Escola de Botucatu, São Paulo, Brasil. Fizeram parte do estudo 37 pacientes. Os dados foram obtidos por meio do instrumento de consulta de enfermagem. Os resultados mostraram predominância de indivíduos com união estável (78%), brancos (92%), com idade entre 30 e 49 anos (51%), com baixo nível de escolaridade e com renda familiar per capita *menor que um salário mínimo. Mais de um terço dos pacientes investigados (35%) apresentavam algum grau de incapacidade física. A associação do baixo perfil socioeconômico com a presença de incapacidades físicas imprime maior vulnerabilidade a essa população, podendo impactar negativamente a sua qualidade de vida.*

DESCRITORES: hanseníase; fatores socioeconômicos; distribuição especial da população; pessoas portadoras de deficiência

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INTRODUCTION

Over history, the measures taken to face the problem of leprosy based on isolating the patient, which could not control its endemic, but contributed greatly to increase the fear and the stigma associated with it. Mandatory isolation, as a recommendation to control leprosy continued until the beginning of the 60's, and was officially abolished in 1962[1].

Known as "Hansen's disease", leprosy is one of the oldest diseases of mankind and it has been described since 600 B.C., India, and Africa are considered its cradle. Mentioned in biblical texts, leprosy was related to impurity and divine punishment which contributed to the increase of prejudice and psychosocial problems[2].

The first cases of leprosy in Brazil were notified in 1600 in the city of Rio de Janeiro, then in the States of Bahia and Pará, it was introduced by settlers and African slaves[2]. In the 40's the high endemicity in the North led the authorities to justify this location because of the tropical climate. However, it is known that in countries with cold weather, endemics have also occurred, and a direct correlation must be established not with the weather, but with the socioeconomic situation of the population[2].

Up to recently, leprosy had no specific treatment. In the 40's, Sulfones were discovered, contributing to outpatient treatment that started in the 60's. After this period, with the advent of Clofazimine in the 70's, and Rifampicin with its bacterial properties, there was the concept of cure for the disease. However, only as of 1989, polychemotherapy was introduced in Brazil, and it became an essential instrument to eradicate leprosy[1].

Although Brazil has experienced an expressive process of change in its profile of morbidity and mortality in the last decades, as chronic-degenerative diseases instead of infectious and parasitic diseases have taken the first positions among main causes of death, leprosy is still a relevant public health problem.

According to the World Health Organization (WHO), up to the beginning of 2006, only six countries had not reached the goal of eradicating leprosy: less than 1 case in 10,000 inhabitants. Brazil is 4th place, with 27,313 cases, which corresponds to a prevalence of 1.5 cases/10,000 inhabitants, behind only of Mozambique, Nepal and Democratic Republic of Congo. Despite there was a 1.47 per 10,000 population decrease in prevalence in Brazil in 2005, the coefficient of detection of new cases did not have analogous decrease, with 40 to 50 thousand new cases diagnosed every year[3].

The goal for elimination in 2004 was achieved by the State of São Paulo, with a prevalence coefficient of 0.44 diseased patients per 10,000 inhabitants. In spite of that, in 2005, 2438 new cases were detected (0.66/10,000 inhabitants), and 76 cases were younger than 15 years old. Among these, 9 % already presented mild to severe physical disabilities in the time of detection, pointing out to late diagnoses[1].

In addition to individual conditions, other factors are related to the endemic levels: unfavorable socioeconomic conditions, poor health, as well as overcrowded houses influence the risk for getting the disease[4]. In the literature, several studies from the 20th century have associated the socioeconomic factor as a predisposing cause of leprosy[5].

A study published in 1996, aiming at knowing the ways of social reproduction (ways of working and living) that form leprosy families, observed that most of them were in outcast groups located in regions were social exclusion is higher[5].

Highlighting this aspect, the Millennium declaration, approved by the General Assembly of the United Nations in 2000, with the plans of all State-Members of the United Nations (UN) to improve the lives of all inhabitants of the planet in the 21st century, established as one of its goals to reduce poverty and famine, presenting several concrete commitments that, if met in the scheduled time, will improve the destiny of mankind in this century[6].

Poverty can be defined as being deprived of conditions that allow individuals to have a life they can value. Being deprived of such may mean insufficient economic conditions to meet your wishes, lack of physical ability to develop some activities, have no access to education and health, and have political and civil rights disrespected[7].

Availability or absence of resources for low income population contributes positively or negatively to living conditions and influences the choice, evaluation, and adherence to recommended treatment[8].

Considering the disabling potential of leprosy, with consequent deformities that may lead to

problems to those affected by it such as decrease in working capacity, limitation of social life and psychological problems, just detecting that cases are high in Brazil is not enough. It is important to consider, also, the context in which the individual is inserted, subsidizing interventions, to enable a better care of this population and their family.

The objective of this study was to know the socioeconomic and demographic profile, and the grade of disability of leprosy affected people seen in Centro de Saúde Escola de Botucatu (Botucatu School Health Center).

METHODS

Descriptive study developed in the School Health Center (CSE), of the Medical School of Botucatu, UNESP. The Program of Leprosy Support has been developed since 1989 and is a reference to the micro-region of Botucatu, Health Regional Directory, DIR XI as of decree 51433 of 12/28/2006 became part of the Regional Department of Health - DRS VI - Bauru.

The Program is developed by a multiprofessional team acting on detection, treatment and follow-up of cases, prevention and treatment of disabilities and surveillance of those in contact with patients. From January 2004 to December 2006, 36 patients were undergoing polychemotherapy (PCT), and 35 were in clinical follow-up, after PCT. Among these, 37 were part of the study. Twenty-seven patients undergoing PCT and 10 patients with finished treatment accepted to take part in the study and gave their written consent. Data were obtained trough an instrument for nursing consultation, collected by nurses working in the program after approval of the Ethical Research Committee of FMB, UNESP.

Sociodemographic variables and grade of disability were assessed using Tukey's multiple comparison test. In the comparison of groups, small letters were used, considering that the proportions followed by, at least, one letter did not differ. Significance level adopted for the tests employed was 5%.

Quantitative study of the variables: family income, clinical form, and treatment situation were performed by frequency distribution, whose outcomes are presented by absolute and relative percentage frequencies.

In order to check the presence of differences in frequencies of the sociodemographic characteristics according to clinical form of the disease, cross-tabulations were performed and the differences underwent Pearson's chi-square test. These assessments were processed using SPSS 12.0 software.

OUTCOMES

Of the 37 patients studied, 14 (38%) had Lepromatous leprosy (L), 11 (30%) Tuberculoid (T), 6 (16%) Borderline (B), 3 (8%) Indeterminate (I), and 3 (8%) Pure Neural Leprosy (PN).

Data referring to socioeconomic and demographic profile are demonstrated on Table 1.

Table 1 - Distribution of patients seen in nursing consultations, according to sociodemographic variables, Botucatu, 2007

Variable	Frequency		Statistic	
	Nº	%	Test value	P value
Gender*				
Male	21/37	57	z=0.97	p=0.33
Female	16/37	43		
Marital status**				
Stable relationship	28/37[a]	78		
Single	4/37[b]	11		
Divorced	3/37[b]	8		
Widow/er	1/37[b]	3		
Race*				
Caucasian	34/37	92	z=6.99	p<0.001
Brown people	3/37	8		
Age group**				
<15	1/37[b]	3		
15 to 29	6/37[b]	16		
30 to 49	19/37[a]	51		
50 to 59	6/37[b]	16		
= 60	5/37[b]	14		
Education**				
Illiterate	3/37[b]	8		
Incomplete Elementary	25/37[a]	68		
Complete Elementary	3/37[b]	8		
Incomplete High School	1/37[b]	3		
Complete High School	5/37[b]	14		
City**				
Botucatu	27/37[a]	73		
DIR XI - Botucatu	9/37[b]	24		
Outside DIR XI - Botucatu	1/37[c]	3		

* z test;
** Tukey's test

Of the 37 referred, 21 (57%) were males, and 16 (43%) were females, there was no statistical significant difference in this variable.

There was statistically significant predominance of the patients in stable relationships,

28 (78%), Caucasians, 43 (92%) with ages ranging from 30 to 49, 19 (51%). Mean age of the patients studied was 42 (*SD*±3.3).

Median of years studied was 4 years with statistically significant predominance of patients with schooling corresponding to Incomplete Elementary Education, (25 - 68%), that is, less than 8 years of study.

Regarding occupation, several industries were involved; most of them (24 - 65%) worked providing services. Among these people, 9 (24%) worked in domestic services (housewife, cleaner, maid), 6 (16%) in civil construction; 3 (8%) in agriculture, 2 (5%) in shops, and 2 (5%) in textile industry. In addition to these activities, 2 (5%) were underage, and 4 (11%) were retired.

Most patients 27 (73%) were from Botucatu, 9 (24%) lived in towns from DIR XI - Botucatu, and one (3%) was from São Paulo.

Sociodemographic variables studied here do not demonstrate associations with clinical forms of the disease.

Mean family income was 1.1 wages (*SD*±1.3).

In Table 2 data referring to family income may be observed.

Table 2 - Distribution of patients seen in nursing consultations according to family income, Botucatu, 2007

Family income	Nº	%
< 0.5 salary	8/37	21
0.5 ├ 1 salary	14/37	38
1 ├ 2 salary	12/37	32
> 2 salary	2/37	5
Not declared	1/37	3

When assessing grade of disability presented, it was observed that most studied patients (24 - 65%) did not present disabilities, however, more than a third (13 - 35%) presented them, 7 (19,0%) with grade I of disability, and 6 (16,0%) with grade II. Of the patients with disabilities, five (13.5%) presented them in more than one follow-up. Inferior limbs were more frequently involved ($p<0.05$).

Data regarding grade of disability are presented on Table 3.

Table 3 - Distribution of patients seen in nursing consultation according to grade of disabilities, Botucatu, 2007

Limb	Grade 0		Grade I		Grade II	
	Nº	%	Nº	%	Nº	%
RE	34/37[a]	92	2/37[b]	5	1/37[b]	3
LE	34/37[a]	92	1/37[b]	5	2/37[b]	3
SRL	33/37[a]	89	1/37[b]	3	3/37[b]	8
SLL	32/37[a]	86	1/37[b]	3	4/37[b]	11
IRL	28/37[a]	76	7/37[b]	19	2/37[b]	5
ILL	28/37[a]	76	7/37[b]	19	2/37[b]	5
HGD	24/37[a]	65	7/37[b]	19	6/37[b]	16

RE and LE: right eye and left eye; SRL and SLL: superior right limb and superior left limb; IRL and ILL: inferior right limb and inferior left limb; HDL: higher disability grade*.

Among patients presenting disability grade I or II, 7 (18%) were undergoing PCT and 4 had finished it (16%).

DISCUSSION

Regarding the forms of the disease, only 3 patients (8%) were Indeterminate, considered as clinical manifestation of the disease[9] whereas the majority, 34 patients (92%) presented borderline, pointing out for a later diagnoses.

In another study, Lepromatous leprosy was also the most frequent and the Indeterminate the less frequent[10].

This implies future complications once the disease has a high disabling capacity, therefore, early diagnoses and suitable treatment prevent the development of physical disabilities that are considered as one of the elements that hinder work and social activities leading to poor living conditions[3].

Therefore, a greater investment in health services is necessary to divulge and give guidelines of this disease, so that individuals have the opportunity to have early detection, decreasing the possibilities of developing disabilities.

Regarding gender, other works observed predominance of males among affected population, differing of the data found in this study, since there was no statistically significant difference in this variable[10-11].

* Grade 0: corresponds to no problems with eyes, hands and feet due to leprosy; Grade I: entails decrease or loss of sensibility in eyes, hands and feet and Grade II: in eyes is related to the presence of lagophthalmos and/or ectropion and/or trichiasis and/or central corneal opacity and/or visual acuity lower than 0.1 or not being able to count fingers at 6 m; in hands and feet, to the presence of trophic lesions and/or traumatic, claw hands, re-absorption, hands, feet drop, and ankle contracture (BRASIL, 2002).

Of the 31 patients studied, (84%) were in economically productive phase (15 - 59), which is an important fact because this is a disease with high disabling potential which interfered dramatically in work and social life of the patient, leading to economic loses and psychological trauma[11].

Time dedicated to school of the individuals studied (mean 4 ± 3.3) was lower compared to the population of Botucatu, that according to the SEADE foundation (2007), in the age group between 15 - 64, in the year 2000, the mean study years was 8.1, as well as to the population of the State of São Paulo, that presented mean 7.64 years of study in the same period.

Regarding family income, it called our attention; the fact that the majority of the population studied (22 - 59%) had family income lower than one minimum salary, being below the poverty line[12]. Only two patients (5%) had family income over two minimum salaries. Thus, it was observed that most patients studied (34 - 92%) had family income below the average income of the city of Botucatu and of the State of São Paulo, which was respectively 2.81 and 2.92 minimum salaries in the year of 2000.

A study conducted in 1996 with leprosy patients in the city of São Paulo, detected that 41.9% of those surveyed had family income higher than 1.8 minimum salary, a percentage that was higher than that observed here, once 32% of patients presented this family income[5].

Income is one of the socioeconomic indicators used to create the Human Development Index (HDI). According to the Human Development Report (HDR) of 2005, Brazil is in 64th position in the world rank regarding income, highlighting inequality: 46.9% of the income is within the richest 10% and only 0.7% within the poorest 10%. It also states that social inequality hinders economic development and benefits of the poorest[13].

Economic aspects may influence the ways to face health problems, and they could be different in an individual according to the stages of health maintenance together with social and psychological aspects[8].

Predominance of professions working with services was observed, including not only general services, but also household services, whose tasks require no qualification and tend to lead to poor working relations. This was in agreement with the poor education observed in most surveyed people.

The study of social reproduction of leprosy in the city of São Paulo identified that most affected people were in intermediate and inferior bracket, working in informal, underpaid and unskilled jobs, corroborating the data observed here[5].

When assessing the grade of physical disabilities, although such classification are done using specific techniques standardized by the World Health Organization and countersigned by the Ministry of Health[3] it was difficulty to compare these data with those from the literature, because of the time assessment was performed and the way data were obtained.

In this study, the grade of disability was assessed when nursing consultation was carried out, and, therefore, with most patients undergoing PCT (27 - 73%) and with the remaining patients after discharge (10 - 16%). In the studies read, this assessment was performed in the stages of diagnoses and discharge, and secondary data were used[1,14].

In the State of São Paulo, in 2005, around 14% of cases started treatment with physical disability, 9% severe and moderate, a percentage that was lower than that found in this study[1].

In a study performed in the city of São José do Rio Preto, interior of São Paulo, with information obtained from charts, it was observed that from 39 patients cared for in 2003, 69.2% were grade 0; 25.6% were grade I; 2.6% grade II, and 2.6% were not assessed at diagnoses. Percentage of patients without disabilities was close to that observed in this study whereas in grade II we had a greater percentage[15].

Physical disabilities may lead to decrease in working capacity, together with limiting social life, this could be worsening, as observed here, when associated with working with services that overall, are not connected with social security, and are badly paid .

CONCLUSION

It was concluded that the population studied was concentrated on less privileged levels of the society, which is in agreement with the profile described in the literature, and it is associated with the risk of being affected by leprosy.

Association of poor socioeconomic profile with the presence of physical disabilities makes this population more vulnerable and may have a negative impact on their quality of life.

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