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Brief communication

Knowledge of the patients regarding leprosy and adherence to treatment

Karlisson Bezerra Lira^{a,*}, João Jaime Giffoni Leite^b, Débora Castelo Branco de Souza Collares Maia^b, Rafael de Mesquita Ferreira Freitas^b, Alexsandra Rodrigues Feijão^a

^a Faculdade Metropolitana da Grande Fortaleza, Fortaleza, CE, Brazil

^b Universidade Federal do Ceará, Fortaleza, CE, Brazil

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ABSTRACT

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. It is known for its great disfiguring capacity and is considered an extremely serious disease to public health worldwide. The state of Ceará ranks 13th in number of cases of leprosy in Brazil, and fourth in Northeastern region, with an average of 2,149 new cases diagnosed every year. This study aimed to evaluate the knowledge of leprosy patients regarding treatment, and to assess the level of treatment adherence and its possible barriers. The study was conducted in the reference center for dermatology, from September 2010 to October 2010, in Fortaleza, Ceará. The study data were collected by means of a structured interview, along with the Morisky-Green test, in order to assess treatment adherence and barriers to adherence. A total of 70 patients were interviewed, out of whom 66 were new cases. The majority of patients were between 42 and 50 years old, and 37 (52.9%) were male. Most patients were clinically classified as presenting multibacillary leprosy (80%), and 78.6% of them were from Fortaleza, Brazil. The Morisky-Green test indicated that 62.9% of patients presented a low level of adherence ($p < 0.005$), despite claiming to aware of the disease risks. However, it was observed that 57.1% of the patients had no difficulty adhering to treatment, while 38.6% reported little difficulty. This study shows that despite the patients claiming to be familiar with leprosy and its treatment, the Morisky-Green test clearly demonstrated that they actually were not aware of the principles of therapy, which is evidenced by the low degree of treatment adherence.

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Leprosy is a chronic contagious infectious disease caused by *Mycobacterium leprae*, an intracellular bacterium that has affinity for both skin cells and Schwann cells of peripheral nerve tissues. This microorganism is acquired through the respiratory route. Clinical manifestations only appear years after the first contact with the bacillus.¹

Leprosy is a reportable disease known for its disfiguring capacity. It is considered an extremely serious disease to public health, both in Brazil and in the world.² In 2010, a total of 211,903 cases of leprosy were reported to the World Health Organization (WHO) from 141 countries or territories.³ Brazil presents high incidence rates of leprosy, and the Northeast

* Corresponding author at: Rua Conselheiro Estelita, 500, Centro, Fortaleza, CE, 60425-480, Brazil.

E-mail address: karlisson@msn.com (K.B. Lira).

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Region is the most affected. The disease is endemic in the state of Ceará, presenting high incidence rates.² In 2010, Ceará reached a detection rate of 25.4 for every 100,000 inhabitants; it ranks 13th among the states in Brazil and the 4th in the Northeast Region, with an average of 2,149 new cases annually.⁴

Despite the myths about this ancient disease, its treatment is possible, especially if a diagnosis is correctly established at early stages of the disease, following the polychemotherapeutic regimen recommended by the Brazilian Ministry of Health and standardized by the WHO. Therapy includes drugs such as dapsone, rifampicin, and clofazimine, among others. These drugs are provided by the WHO without charge. However, Brazil remains the second country in the world in number of cases of leprosy, despite all efforts to eradicate this disease. In addition, Brazil is the most affected country in South America, accounting for 80% of all reported cases.⁵

Two major challenges must be overcome in order to reduce leprosy prevalence. The first challenge is the long duration of treatment, which depends on clinical features, varying from six months to one year.¹ The second challenge are the inflammatory and hypersensitivity reactions during treatment, due to *M. leprae* antigen release.

After starting the appropriate therapy, patients no longer transmit the disease. However, because of the challenges mentioned above, therapy is frequently abandoned, which leads to disease dissemination, considering that treatment adherence is closely related to disease control.⁶ Thus, this study aimed to evaluate the knowledge of leprosy patients about the treatment, and to detect the level of treatment adherence and its possible difficulties.

An exploratory-descriptive quantitative survey was carried out in this study. The research was conducted at the Centro de Referência Nacional em Dermatologia Sanitária Dona Libânia, from September to October 2010, Fortaleza, Ceará, and approved by the Ethics Committee of the center (protocol number 031/2010).

The sample consisted of 70 patients with confirmed diagnosis of leprosy. Patients on treatment or not, BCG vaccinated or not (presence of vaccine scar) were included; patients under 18 years of age, those who had completed treatment, or those without a confirmed diagnosis were excluded. In order to participate in this survey, patients had to sign an informed consent; their anonymity was preserved.

This study used a structured questionnaire ascertaining socioeconomic characteristics of the subjects, such as age, gender, education level, and questions concerning individual knowledge about the disease. To assess the level of treatment adherence, the Morisky-Green test,⁷ which consists of four yes/no questions, was used. Positive answers scored no points, while each negative answer represented one point. When all questions were answered negatively, a maximum of four points was obtained, which indicated high degree of adherence; a single positive answer was sufficient to indicate low treatment adherence.

The degree of difficulty to adhere with treatment was also assessed.⁸ This comprised 10 adherence-related questions, for which responses were given on a scale: totally agree, partially agree, undecided, partially disagree, and strongly disagree,

Table 1 – Patient characteristics according to the level of knowledge and difficulties to adhere with treatment.

Variable	n	%
<i>Knew about the disease before diagnosis</i>		
Yes	37	52.9
No	33	47.1
<i>Researched to learn more about the disease after diagnosis</i>		
Yes	43	61.4
No	27	38.6
<i>Knowledge of the medications used</i>		
Yes	7	10.0
No	63	90.0
<i>Knowledge of how many medications were used</i>		
Yes	67	95.7
No	3	4.3
<i>Knowledge regarding treatment duration</i>		
Yes	52	74.3
No	18	25.7
<i>Difficulties for treatment</i>		
No complaint	21	30
Bias	4	5.7
Displacement	8	11.4
Reaction to medication	18	25.7
Delay in treatment	16	22.9
Change of routine	3	4.3

with values varying from 5 to 1, respectively. The results were interpreted by the Likert scale: 10 to 20 points represented no difficulty in adhering with treatment; 21 to 30, little difficulty; 31 to 40, moderate difficulty; and 41 to 50, great difficulty in adhering with treatment. Data were evaluated through Pearson's chi-squared test. For the univariate analysis, a binomial test was used to analyze the equality of proportions when there were only two categories of variables; when there were more than two categories, the multinomial test was used. The Statistical Package for Social Sciences (SPSS 15.1 for Windows) was used for data analysis. Absolute and relative frequencies were used for clinical characterization of patients, and the chi-squared test was used to assess correlations.

The socioeconomic and clinical profile of the patients showed that 52.9% of patients were male and 47.1% were female. In relation to marital status, 44.3% were single, 50% married, and 5.7% widowed. Most patients lived in Fortaleza, while 24.1% lived in the countryside of the state of Ceará. Concerning the number of inhabitants in their households, 45.7% declared to live with one to three people, and 42.9% declared to live with four to six other people. Regarding the educational level, 45.7% had completed middle school.

Most patients (80%) presented multibacillary leprosy, while 20.0% presented the paucibacillary type. In relation to BCG vaccination, it was observed that 49 studied patients (70%) had a vaccination scar. Additionally, 94.3% of patients were new cases undergoing treatment for the first time.

Table 1 demonstrates the patients' knowledge of the disease before being medically assisted and knowledge of

treatment. It was observed that 52.9% had heard about the disease at diagnosis, and 61.4% had searched for more information about leprosy. However, 90% of the patients did not know which medications they had used, but 95.7% were aware of how many different drugs they were taking, and 74.3% knew the duration of therapy. Of all patients, 30% had no complaints about the treatment, but 27.5% had complained of drug reactions and 22.9% of treatment length.

Regarding the Morisky-Green test, 62.9% of patients presented low level adherence, while 37.1% were classified as patients with high adherence rate ($p < 0.005$). Finally, regarding the degree of difficulty in adhering with treatment, it was found that 57.1% of patients had no difficulty, 38.6% had little difficulty, and only 4.3% had moderate difficulty.

Data obtained with the Morisky-Green test was compared with the following variables: "researched to learn more about the disease after diagnosis", "knowledge of treatment duration", and "knowledge of which drugs they were using". In the association between the Morisky-Green test and the variable "researched to learn more about the disease after diagnosis", even though they Despite being in the low level adherence group ($n = 44$), 27 patients (61%) researched to learn more about the disease. Similarly, 16 (62%) patients in the high-adherence group ($n = 26$) also researched to learn more about leprosy. Regarding the variable "knowledge of treatment duration", 80% of low adherence patients knew the duration of treatment, while 65% of high adherence patients were aware about treatment duration. Finally, 14% ($n = 6$) of the low adherence patients knew the name of the medications and only one patient (4%) out of the 26 high adherence patients claimed to know the name of the medications.

The association between the degree of difficulty in adhering with treatment and the variable "researched to learn more about the disease after diagnosis", 26 (59%) out of 44 patients who had no difficulty in adhering with treatment claimed to have researched to learn more about the disease. Out of the 24 patients with little difficulty, 15 (63%) reported the same, while 100% ($n = 2$) of the patients categorized as having moderate difficulty in treatment adherence said to have researched more information on the disease.

Concerning the variable "knowledge of treatment duration", 73% of patients who had no difficulty in adhering with treatment were aware of the treatment duration, as well as 79% of those who had little difficulty, and 50% of those who had moderate difficulty. Finally, concerning the variable "knowledge of the name of the drugs they are using", out of the 44 patients who presented no difficulty in adhering treatment, 91% ($n = 40$) knew the name of the medications. 88% of patients who had little difficulty also knew the name of the medications and so did the two (100%) patients who reported moderate difficulty.

Leprosy remains a serious public health problem worldwide, despite the mobilization of several health agencies attempting to eradicate this disease. Thus, it is necessary to do more research regarding not only the epidemiological aspects, but also the obstacles concerning disease management, such as treatment adherence, since untreated patients play an important role in the transmission and spread of *M. leprae*.

In the present study, no significant differences were observed when comparing genders, while other studies have found a higher frequency of disease incidence in male patients. When analyzing the education level, 3% of patients were illiterate and 70% had finished middle school. Parra⁹ identified that 75% of patients had some degree of education, while 5% were illiterate. These findings reflect the social status of individuals affected by this disease, i.e., the observed results may reflect the social exclusion of this population. The predominant age group in this study was 42 to 50 years old, which is similar to that observed by Hinrichsen et al.¹⁰ and Barro.¹¹

An epidemiological study by Resende et al.¹² revealed the prevalence of cases with clinical classification of multi-bacillary type, similarly to what was observed in this study, suggesting a rather late diagnosis. BCG scar was found in 70% of the interviewed patients ($p < 0.001$). Similar data were found in the study of Ferreira,¹³ who reported the presence of scar in 76% of their cases. Studies by Zodpey et al.¹⁴ showed that BCG vaccine was effective against leprosy, presenting levels of protection ranging from 36% to 90%.

78.6% of the patients were from Fortaleza, similar to what was observed by Gomes et al.¹⁵ Considering that the Centro de Referência Nacional em Dermatologia Sanitária Dona Libânia is located in Fortaleza, most patients are expected to be from Fortaleza and surroundings.

The two major complaints concerning leprosy therapy were those related to drug reactions and treatment durations. These complaints may have influenced the Morisky-Green test, which revealed low level adherence in the interviewed patients. Due to the lack of research using this scale with leprosy patients, the obtained data were compared with those of Cunha et al.,¹⁶ who used the same test to analyze treatment adherence in hepatitis C patients.

Of the 70 diagnosed patients, 53% claimed to have heard about leprosy before knowing they were sick. Conversely, Resende et al.¹² observed that 83.3% of leprosy patients did not know about the disease before acquiring it, and that 50% of them, even after receiving care, were still unaware of the disease, including its clinical-epidemiological aspects.

Interestingly, this study shows that patients claiming to know the disease and its treatment were actually not aware of the principles of leprosy therapy based on the Morisky-Green test results, which evidenced low level treatment adherence. Identifying the main reasons why patients do not properly adhere with treatment will help health professionals to find rapid and efficient solutions to solve this important issue. Additionally, participation of a multidisciplinary staff is important to promote knowledge of this disease, which may help overcoming problems concerning treatment failure and disease dissemination.

Conflict of interest

All authors declare to have no conflict of interest.

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