COMUNICATION

Quality of life in leprosy: a comparative analysis between patients in the Amazon region and patients in Santo André in the ABC region of São Paulo, Brazil*

Qualidade de vida em hanseníase: análise comparativa entre pacientes da região Amazônica com pacientes da região do ABC

Rodrigo Sestito Proto [1]
José Ricardo Carvalho Lima Rehder [3]
Rodrigo Interlandi Angelucci [5]
Carlos D'Apparecida Santos Machado Filho [2]
Maurício Pedreira Paixão [4]

Abstract: This study analyzed the quality of life of individuals with leprosy and compared quality of life indexes of patients in two different socioeconomic scenarios. The study was conducted at the leprosy clinic of the ABC School of Medicine, São Paulo, Brazil and during visits to the populations living along the Purus River in the Brazilian state of Amazonas. The Dermatology Life Quality Index (DLQI) was used to evaluate the patients. Quality of life was found to be impaired in 76.9% of the patients evaluated in the Amazon compared to 19% of the patients in Santo André.
In the group of patients in the Amazon who had sequelae of the disease, quality of life was impaired.
Keywords: Quality of Life Indexes; Leprosy

Resumo: Nesse estudo analisou-se a qualidade de vida de indivíduos com hanseníase, além da comparação de índices de qualidade de vida entre duas realidades sócio-econômicas distintas.O trabalho foi realizado no ambulatório de hanseníase da Faculdade de Medicina do ABC-SP e através de visitas à população ribeirinha do Rio Purus , Estado do Amazonas, utilizando-se o Índice de Qualidade de Vida Dermatológico (IQVD).Observou-se que 76,9% dos pacientes avaliados na Amazônia tinham qualidade de vida comprometida, enquanto 19% em Santo André apresentavam esses resultados.No grupo do Amazonas, quem possuía sequela apresentava qualidade de vida comprometida.
Palavras-chave: Hanseníase; Índices; Vida

INTRODUCTION

The concept of quality of life encompasses physical activity, psychological well-being, the patient's degree of independence and his/her social relationships. [1] Skin diseases exert a considerable impact on social relationships, psychological status and on the daily routine of these patients. [2,3]

Unlike the traditional clinical evaluation tools, there are few references available in the medical literature that deal specifically with quality of life studies. For this reason, questionnaires need to comply with basic principles and must be interpreted correctly. [1] When applying the questionnaire, the domains evaluated must obey certain criteria of reliability, consistency, sensitivity and validity. [4-7] The principal index used in dermatological studies is the Dermatology Life Quality Index (DLQI) created by Finlay and Kahn in Wales. [3]

Leprosy continues to represent a severe public health issue in Brazil, with enormous psychological

Received on 14.05.2009.
Approved by the Advisory Board and accepted for publication on 18.06.10.
* Study conducted in the leprosy outpatient clinic, Department of Dermatology, ABC School of Medicine (FMABC), São Paulo, Brazil.
Conflict of interest: None / *Conflito de interesse: Nenhum*
Financial funding: None / *Suporte financeiro: Nenhum*

[1] Preceptor, Department of Dermatology, ABC School of Medicine (FMABC), São Paulo, Brazil.
[2] Head of the Department of Dermatology, ABC School of Medicine (FMABC), São Paulo, Brazil.
[3] Head of the Department of Ophthalmology, ABC School of Medicine (FMABC), São Paulo, Brazil.
[4] Preceptor, Department of Dermatology, ABC School of Medicine (FMABC), São Paulo, Brazil.
[5] Preceptor, Department of Ophthalmology, ABC School of Medicine (FMABC), São Paulo, Brazil.

repercussions resulting from the physical disabilities caused by the disease. These disabilities, in fact, constitute a major cause of social stigmatization, resulting in patients' isolation from society and consequently leading to a decrease in their quality of life. [8-10]

In this study, a standardized questionnaire was used to evaluate the impact of leprosy on the daily life of these patients, analyzing their quality of life and whether there were any associations with the clinical and epidemiological characteristics of the disease. In addition, the quality of life indexes in two distinct socioeconomic scenarios were compared.

METHODS

The study was conducted in the leprosy outpatient clinic of the ABC School of Medicine in Capuava, Santo André and during visits to the populations living along the banks of the Purus River, an affluent of the Solimões River, in the Brazilian state of Amazonas.

In the Brazilian Amazon, healthcare agents are specifically trained by the State Health Department to diagnose, notify, treat and follow-up patients with leprosy. In addition, they provide post-discharge follow-up and counsel patients on the prevention of disabilities caused by the disease. These services are all provided in the patients' own homes.

Data were collected by interviewing 21 patients in Santo André and 26 patients from the populations living along a riverbank in the Amazon region. Only patients in treatment or undergoing post-discharge follow-up were included in the study, with patients whose diagnosis had not been confirmed and those who had not yet initiated treatment being excluded from the study. The Dermatology Life Quality Index (DLQI) [3] was used. The questionnaire was applied to each patient individually by the same investigator, a dermatologist, in the two geographical regions participating in the study. Physical examination, including the detection of disabilities and diagnosis of the clinical forms of leprosy, was performed at the same time that the questionnaire was applied.

This questionnaire is composed of ten questions, the scores for each question being interpreted as: 0: not at all or not relevant; 1: a little; 2: a lot; 3: very much. The final overall score of the questionnaire is interpreted as follows: 0-1: no effect at all on patient's life; 2-5: small effect on patient's life; 6-10: moderate effect on patient's life; 11-20: very large effect on patient's life or 21-30: extremely large effect on patient's life. [3]

The quantitative variables measured were described as means and standard deviations of the mean when distribution was normal or medians and quartiles when it was not. The normalcy of the data was tested using the Kolmogorov-Smirnov test. If data were normal, the variables were compared between the two groups using Student's t-test; otherwise the Mann-Whitney test was used.

Qualitative variables were described as the absolute number and percentage of patients, and were compared between the groups using the chi-square test or Fisher's exact test with the Monte Carlo simulation when the chi-square test could not be applied.

A significance level of 5% was adopted throughout the statistical analysis, which was performed using the SPSS statistical software package, version 15.

RESULTS

The percentage of patients with lepromatous leprosy was higher (68.1%) in the Amazon region. In general, quality of life was poorer in the Amazon, with 76.9% of patients in that region evaluating their quality of life as poor compared to only 19% in Santo André ($p<0.001$). These results are shown in Figure 1, which shows the differences in the overall mean scores of the two groups. The Santo André group had a lower score compared to the group of patients in the Amazon region. This difference is reflected in the medians shown in the darker lines inside the box.

The majority of the patients in the Amazon had sequelae associated with poor quality of life, as evaluated by their score and shown in Table 1.

DISCUSSION

One possible explanation for the greater number of cases of lepromatous leprosy in the Amazon is that in addition to this being a hyperendemic region with precarious socioeconomic conditions, detec-

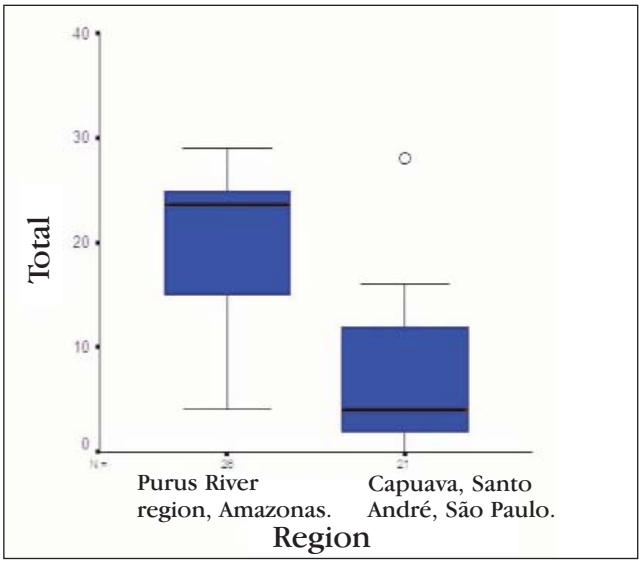

Figure 1: Distribution of the total quality of life index score in the areas studied

TABLE 1: Presence of sequelae in relation to quality of life score, evaluated according to group

Group	Sequelae	Good quality of life	Poor quality of life	p-value
Amazonas (Purus River)	Absent	3 (50.0%)	1 (5.0%)	
	Present	3 (50.0%)	19 (95.0%)	0.028
	Total	**6**	**20**	
Santo André (Capuava)	Absent	15 (88.2%)	2 (50.0%)	
	Present	2 (11.8%)	2 (50.0%)	0.148
	Total	**17**	**4**	

Number of patients (%) Fisher's exact test by Monte Carlo simulation

tion of cases is often delayed; consequently, these patients progress untreated to the more severe forms of the disease. [9]

The higher mean scores found in the Amazon may be explained by the fact that in this region the disease is not diagnosed in its early phases because of the poor access to healthcare services and the lack of trained professionals, with the result that the patients progress to more severe forms of the disease (multibacillary forms). Since they are not provided with treatment and are not followed-up, they develop sequelae that are disabling and disfiguring, leading to a decline in quality of life and exerting an impact on their hunting and agricultural activities, which are important in this region of the Amazon. [9,10]

The high scores found in the quality of life indexes evaluated in the present study show the significant effect of this disease on the quality of life of patients in the Amazon region who had disabling sequelae. The differences found between the ABC region in the state of São Paulo and the Amazon region were statistically significant. ❑

REFERENCES

1. Halioua B, Bemmont MG, Lunel F. Quality of life in Dermatology. Int J Dermatol.2000;39:801-6.
2. Jawett S, Ryan T.Skin disease and handicap: An analysis of the impact of skin conditions. Soc Sc Med. 1985;20:425-9.
3. Finlay AY, Ryan T. J.Disability and Handicap in Dermatology. Int J Dermatol.1996;35:305-11.
4. Guyatt GH, Feeny DH. Measuring health-related quality of life. Ann Inter Med. 1993;118:622-9.
5. Aaronson NK.Quality of life assessment in clinical trials: Methodologic issues.Control Clin Trials. 1989;10:195-208.
6. Greenfield S, Nelson EC. Recent developments and future issues in the use of health status assesment measures in clinical settings. Med Care. 2000;30:MS23-41.
7. Wiklund I, Dirrenas E, Wahl W. Factors of importance when evaluating quality of life in clinical trails. Control Clin Trials.1990;11:169-79.
8. Wang CH. Quality of life and health for persons living with leprosy. Nurs Sci Q.1997;10:144-5.
9. Maluf SA, Pedrazzani ES, Pedroso M, Toyoda CY. Prevenção de incapacidades em hanseníase: realidade numa unidade sanitária. Rev Bras Enferm. 1985;38:319-28.
10. Martins BDL, Torres FN, Oliveira MLW. Impacto na qualidade de vida em pacientes com hanseníase. An Bras Dermatol. 2008;83:39-43.

MAILING ADDRESS / ENDEREÇO PARA CORRESPONDÊNCIA:
Rodrigo Sestito Proto
Rua Vieira de Morais ,1196,
04617 003 - Campo Belo. São Paulo - SP, Brazil
Phone./Fax: 11 5542 0114 / 11 5531 3271.
email: rodrigoproto@hotmail.com

How to cite this article/*Como citar este artigo:* Proto RS, Machado CDS, Rehder JR, Paixão MP, Angelucci RI. Quality of life in leprosy: a comparative analysis between patients in the Amazon region and patients in Santo André in the ABC region of São Paulo, Brazil. An Bras Dermatol. 2010;85(6):939-41.