

Profile of patients affected by Hansen's disease seen at the Outpatient Clinic of Dermatology at Hospital Evangélico de Curitiba *

Perfil dos pacientes acometidos pela hanseníase atendidos no Ambulatório de Dermatologia do Hospital Evangélico de Curitiba

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Abstract: BACKGROUND: Leprosy or Hansen's disease is a chronic infectious disease with worldwide distribution. Although it is a curable disease, it remains as a public health problem, with Brazil being the second most endemic country in the world. The skin lesions and neural damage, which lead to physical disabilities, affect the patients' self-esteem, cause a decrease in quality of life and interfere in the patients' lives.

OBJECTIVE: Identify the profile of the patients affected by leprosy seen at the Outpatient Clinic of Dermatology of Hospital Evangélico de Curitiba and characterize the levels of quality of life of the sample in the week prior to the survey by means of the Dermatology Life Quality Index questionnaire.

METHOD: Application of the Dermatology Life Quality Index to 22 patients diagnosed with leprosy in the period from May to October 2009.

RESULTS: Among the 22 patients who participated in the study, 55% were male and 45% were female, with a mean age of 50.2 years. The scores obtained with the Dermatology Life Quality Index ranged from 1 to 25 points, with a mean of 10.23. Most of the patients (50%) had scores in the range severe or very severe; 31.8% of the patients obtained scores in the range mild or moderate, and 18.2% of the patients reported that there was no impairment of their quality of life.

CONCLUSION: The profile of the patients affected by leprosy in this study were men, with a mean age of 50 years and presenting the multibacillary form of the disease. The application of the Dermatology Life Quality Index questionnaire allowed us to verify that the score severe or very severe for quality of life was predominant in the sample, with higher impact on women and no significant difference concerning pauci or multibacillary leprosy.

Keywords: Dermatology; Indicators of quality of life; Leprosy

Resumo: FUNDAMENTOS: A hanseníase é uma enfermidade infecto-contagiosa, com distribuição mundial. Apesar de curável, permanece como um problema de saúde pública, sendo o Brasil o segundo país mais endêmico do mundo. As lesões cutâneas e o acometimento neural, que levam às principais incapacidades físicas, pioram a autoestima dos doentes, levam a uma queda da qualidade de vida e interferem na vida dos mesmos.

OBJETIVO: Traçar um perfil dos pacientes acometidos pela hanseníase, atendidos no Ambulatório de Dermatologia do Hospital Evangélico de Curitiba, e caracterizar os níveis de qualidade de vida da amostra na semana prévia à pesquisa, por meio do questionário *Dermatology Life Quality Index*.

MÉTODO: Aplicação do *Dermatology Life Quality Index* em 22 pacientes diagnosticados com hanseníase no período de maio a outubro de 2009.

RESULTADOS: Em meio aos 22 pacientes que participaram do estudo, encontraram-se 55% do sexo masculino e 45% do sexo feminino, com idade média de 50,2 anos. Os escores obtidos na aplicação do *Dermatology Life Quality Index* variaram de 1 a 25 pontos, sendo a média 10,23. A maioria dos pacientes (50%) apresentou escore na dimensão do grave ou muito grave; 31,8% dos pacientes, do leve ao moderado, e 18,2% dos pacientes informaram que não houve comprometimento da qualidade de vida.

CONCLUSÃO: O perfil de pacientes acometidos pela hanseníase encontrado neste estudo foram homens, com idade média de 50 anos e com forma multibacilar. A aplicação do *Dermatology Life Quality Index* permitiu verificar que o escore de comprometimento de qualidade de vida grave ou muito grave foi predominante na amostra, tendo mais impacto nas mulheres e não apresentando diferença em relação à hanseníase pauci ou multibacilar.

Palavras-chave: Dermatologia; Hanseníase; Qualidade de vida

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INTRODUCTION

Leprosy is a chronic, infectious and granulomatous disease with worldwide distribution. In ancient civilizations, the disease was considered a punishment, and patients were segregated from society and required to wear a special outfit so that they could be recognized at a distance. The oldest reports about the disease date back to 4266 BC in Egypt, 500 to 2000 BC in the sacred books of India and 1100 BC in China. These barbaric attitudes, associated with the deformities and mutilations caused by the disease led to prejudice and discrimination, which persist to this day.¹

The etiologic agent of the disease is *Mycobacterium leprae*, discovered in 1873 by Armauer Hansen. The only source of infection is the human being and its transmission occurs directly from untreated bacilliferous patients, who eliminate bacilli through the upper airways, to healthy individuals.¹

The disease is classified into two stable poles and two intermediate unstable forms: the immune-positive pole - Tuberculoid Leprosy - and the negative-immune pole - Lepromatous Leprosy. The unstable forms are Indeterminate Leprosy and Borderline Leprosy, which evolve to one of the stable poles along the natural evolution of the disease.¹

It is characterized by dermatological and neurological signs and symptoms. The former vary from hypoesthetic hypopigmented macules with irregular borders to progressive and diffuse infiltration of the skin and mucous membranes of the upper airways. Involvement of the latter manifests with neural lesions (mainly peripheral nerves), which depend on the form that affects the patient.¹

For therapeutic purposes and in order to reduce the prevalence rate of leprosy in endemic countries, the World Health Organization (WHO) classifies the disease into paucibacillary and multibacillary according to number of lesions and neural involvement.¹

Paucibacillary forms show preserved cellular immunity, negative skin smear, positive Mitsuda, fewer than five skin lesions and one compromised nerve trunk (including indeterminate and tuberculoid forms), while multibacillary forms present reduced or absent specific immunity to the bacillus, positive skin smear, more than five skin lesions and/or more than one compromised nerve trunk (lepromatous and borderline forms).¹

Despite being a curable disease, leprosy remains a public health problem, and Brazil is considered the second most endemic country in the world. The last data recorded in 2006 show 43,652 new cases, of which 1510 were reported in the state of Paraná. In the same year, the rate of detection of the disease in the city of Curitiba was 0.37 cases/10,000

population, and the number of new cases was 66.^{2,3}

The historical association of the disease with stigmas still remains as the idea of a mutilating and incurable disease persists, provoking attitudes of rejection and discrimination of the patient, with their possible exclusion from society. In addition, the skin lesions and neural involvement, which cause physical disabilities, cause the patients' self-esteem to get even worse, leading to a decrease in quality of life and interfering with various aspects of their lives, such as appearance, work and marriage.⁴

According to Cleary et al., the term health-related quality of life "refers to various aspects of a person's life that are affected by changes in their health and are important to their quality of life."⁵ In other words, it refers to the impact of the disease or its aggravation on quality of life.

Medical interest in this field has been growing in recent decades, which has resulted in the development of several questionnaires assessing health-related quality of life aimed at measuring the problem and its consequences objectively, allowing for a better therapeutic approach of the patients. One of the dermatology-specific questionnaires assessing health-related quality of life is the *Dermatology Life Quality Index* (DLQI), developed by Finlay and Khan in the UK in 1994, translated and validated in the Portuguese language and other 13 languages.⁴

This paper aimed to identify the profile of the patients affected by leprosy seen at the Dermatology Outpatient Clinic of Hospital Evangélico de Curitiba, analyzing sex, age and form of the disease. It evaluated how leprosy affected these patients' quality of life in the week prior to the survey by means of the DLQI (Dermatology Life Quality Index) questionnaire. Moreover, it correlated the scores with sex and form of the disease (paucibacillary and multibacillary).

MATERIAL AND METHODS

This study was approved by the Research Ethics Committee of Sociedade Evangélica Beneficente de Curitiba, without restrictions and safeguarding all the ethical issues of confidentiality and identification of the participants.

This was an observational, clinical-epidemiological, cross-sectional study.

The study included 22 individuals of both sexes over 22 years old. These patients were randomly selected among the patients with leprosy followed up at the Outpatient Clinic of Dermatology of Hospital Universitário Evangélico de Curitiba.

For data collection, all patients were required to complete the *Dermatology Life Quality Index*, adapted and validated into Portuguese (DLQI-BRA),

from May to October 2009. This questionnaire consists of 10 questions related to quality of life regarding skin problems. It is divided into six areas: work, leisure, personal relationships, treatment, symptoms and feelings, with four response alternatives, corresponding to scores from 0 to 3. The maximum score is 30 and the minimum score is 0, with 30 representing higher impairment. For registering the patients' comments, we used the data collection protocol itself.

Before each interview, the patients invited to participate in the study were fully informed of the objectives, rationale and methodology of the investigation. Their permission was obtained by signing the informed consent form.

To differentiate between paucibacillary and multibacillary forms, we reviewed the medical records of the patients interviewed.

After completion of the DLQI-BRA by all patients, their scores were verified. The higher the score, the greater the impairment of the individual's quality of life. The scores are interpreted as follows: no impairment of the patient's quality of life (0-1), mild impairment (2-5), moderate impairment (6-10), severe impairment (11-20) or very severe impairment (21-30).

The data obtained were statistically analyzed by means of the *Welch Two Sample t-test* and *Fisher's Exact Test*, with a significance level criterion of 5% ($p < 0.05$). The data were presented in the form of charts and graphs in real values and percentages.

RESULTS

22 DLQI-BRA questionnaires were applied to 12 (54.5%) male patients and 10 (45.5%) female patients. Their age ranged from 25 to 73 years, with a mean of 50.2 years. Of these patients, 15 (68.18%) were classified as multibacillary and 7 (31.8%) as paucibacillary.

The scores obtained with the application of the DLQI questionnaire ranged from 1 to 25 points, with a mean of 10.23 ± 7.79 points. Most patients (50%) presented severe or very severe impairment of quality of life in the week prior to the study, 31.8% of the patients presented mild to moderate impairment, and only 18.2% of the patients reported no impairment (Chart 1).

The scores of the female patients varied from 3 to 25, and the mean was 13.5. In comparison, the scores of the male patients varied from 1 to 18, with a mean of 7.5 (Graph 1). There were statistically significant differences between the scores of both sexes ($p = 0.04$).

Among the 12 male patients, 10 presented the multibacillary form (MB) and 2 presented the paucibacillary form (PB). Among the 10 women, five developed the multibacillary form and 5 developed

the paucibacillary form. There was no statistically significant difference in the occurrence of MB and PB forms between the sexes ($p = 0.17$).

There was no statistically significant difference between the mean score of the MB and PB forms ($p = 0.63$), as shown in Chart 2.

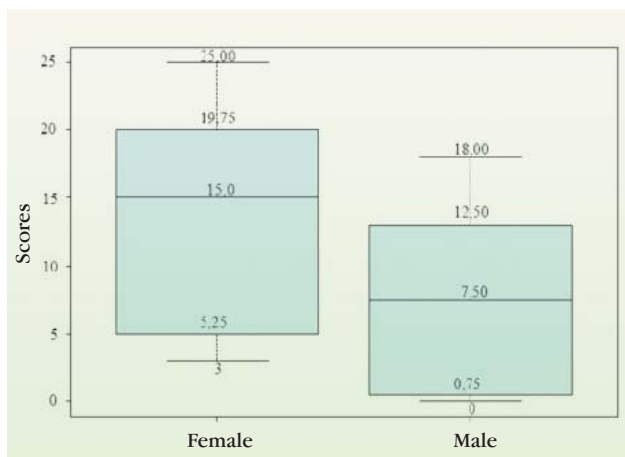
Eleven patients left comments at the end of the data collection protocol, and all of them had severe or very severe impairment (score ≥ 11) of quality of life. There were comments in relation to physical limitations (PL), such as decreased visual acuity and deformities of hands and feet; and comments regarding the aesthetic aspect (AA), such as prejudice in relation to macules and visible lesions. Four patients reported that the disease caused physical limitations, and seven patients stated that the disease interfered with the aesthetic aspect (Charts 3 and 4).

There was no statistically significant difference in relation to patients' sex and type of comment left at the end of the questionnaire (physical limitation or aesthetic aspect) or in relation to form of the disease and type of comment; their values being $p = 0.24$ and $p = 1.0$, respectively.

DISCUSSION

Leprosy is a disease of national importance, putting Brazil in second place in the world due to the high incidence rates and prevalence of the disease in the country. The disease affects men and women, causing serious bio-psycho-social and economic losses, which will culminate in a noticeable decline in quality of life.⁶

The identification of the several effects of leprosy on a patient's life is a way of understanding how these individuals experience the reality and impact of the disease in a specific social context, with the various complexities that affect them. After all, there are numerous reports of patients who left work and



GRAPH 1: Distribution of scores by sex

CHART 1: Classification of impairment of quality of life

Impairment of quality of life	Number of patients
None	4
Mild	6
Moderate	1
Severe	9
Very severe	2
Total	22

stopped being productive due to the disease. Aquino et al. claim that leprosy is a disease with a highly disabling potential, drastically interfering with the patient's social life and work, which causes great economic losses and psychological trauma.⁷

Several studies highlight the psychosocial impact of the dermatosis, reporting situations of discrimination or other stigmatizing experiences related to problems of self-esteem, social isolation and rejection.⁸

Quality of life is assessed according to the individual's perception of himself and his life. It is important to consider that the dermatosis is one of the aspects that can influence quality of life and that patients with the same disease but with different personal characteristics may suffer different losses. Some authors report the social isolation that people with skin problems face due to the association made between skin disease and infection or lack of care.⁸

The interpretation of the data obtained in this study confirms the significant impact of leprosy on patients' quality of life, as indicated by the high scores obtained with the application of the DLQI-BRA questionnaire. This questionnaire on quality of life has been used as a parameter of severity in various dermatoses in more than 130 published articles. Both the authors of the original questionnaire and researchers from other countries have indicated this instrument as practical, reliable and easy-to-use in the evaluation of results on quality of life specific to dermatology.^{4,9,10}

The DLQI scores obtained vary according to the sample. In a study by Zogbi et al., 174 patients with different skin conditions were evaluated, with a mean

CHART 2: Distribution of scores by form of the disease

Form	Number	Mean	Standard deviation of score
MB	15	10.80	7.88
PB	7	9.00	8.06
Total	22	10.23	7.79

CHART 3: Patient's sex x aesthetic aspect (AA) and physical limitation (PL)

Sex	AA	PL	Total
Female	5	1	6
Male	2	3	5
Total	7	4	11

score of 7.12. Chronic skin diseases such as psoriasis, atopic dermatitis and acne achieved high scores with the application of the DLQI in this study. Of these diseases, psoriasis obtained the highest mean score (10.31), a value very close to that obtained in this study on leprosy.¹⁰

The scores obtained in a study by Martins et al. ranged from 1 to 25 points, and most patients had a score that represented severe or very severe impairment, which corroborates the data from this study, in which 50% of the patients obtained the same score.⁴

Leprosy was predominant among males in our sample, which corroborates other studies.⁶ However, other analyses have found a higher prevalence of the disease among females.^{4,11}

Other studies show a stronger relationship between impairment of quality of life and patients with the multibacillary form of leprosy.⁶ However, although the average score was higher for the multibacillary form, this difference was not statistically significant.

CONCLUSION

The profile of patients affected by leprosy in this study corresponded to men, with a mean age of 50 years and presenting the multibacillary form of the disease.

The application of the DLQI-BRA questionnaire allowed us to verify that the scores for severe or very severe quality of life were predominant in our sample.

Leprosy can impair a patient's daily life and personal relationships, with a great social and psychological impact. In our study, this impact was especially associated with women, with no statistically significant difference regarding the pauci or multibacillary form of leprosy. □

CHART 4: Form of the disease x aesthetic aspect (AA) and physical limitation (PL)

Form	AA	PL	Total
MB	5	3	8
PB	2	1	3
Total	7	4	11

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