

Quality of life of patients with paucibacillary leprosy*

Qualidade de vida em pacientes com hanseníase paucibacilar

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Abstract: BACKGROUND - Leprosy, an infectious disease caused by *Mycobacterium leprae*, can affect the skin and the peripheral nervous system and, depending on the level of involvement, it can lead to severe deformities. Leprosy is classified into two major groups: paucibacillary (up to five lesions) and multibacillary (more than five lesions). The deformities that appear during the progress of the disease can affect the quality of life.

OBJECTIVE - To assess quality of life of patients with paucibacillary leprosy diagnosed and treated early in the outpatients' clinic.

METHODS - The Dermatology Life Quality Index questionnaire and ShortForm36 were applied to 49 outpatients undergoing treatment at the Leprosy Multidisciplinary Group of the Hospital das Clínicas of the Faculdade de Medicina of the Universidade de São Paulo.

RESULTS - The majority of the patients (63%) did not show impairment of the quality of life, according to the results obtained by the Dermatology Life Quality Index questionnaire. In the questionnaire Short Form-36, the scores assessed showed slight impairment of the quality of life.

CONCLUSION - On this study, we can conclude that this group of patients, with paucibacillary leprosy, did not show important impairment of the quality of life. Therefore we can conclude that the earlier the diagnosis and the treatment the lesser the influence on the quality of life.

Keywords: Dermatology; Leprosy; Quality of life; Questionnaires

Resumo: Fundamentos - A hanseníase, doença infecciosa causada pelo *Mycobacterium leprae*, pode acometer a pele e o sistema nervoso periférico e de acordo com o grau de acometimento, levar a graves deformidades. É classificada em dois grandes grupos: paucibacilar (até cinco lesões) e multibacilar (mais de cinco lesões). As deformidades que podem ocorrer durante a evolução da doença levam ao comprometimento da qualidade de vida.

OBJETIVO - Avaliar a qualidade de vida nos pacientes com hanseníase, do grupo paucibacilar, diagnosticados e tratados precocemente e em tratamento ambulatorial.

MÉTODOS - Aplicação dos questionários Dermatology Life Quality Index e Short Form-36 a 49 doentes em tratamento no Ambulatório do Grupo Multidisciplinar de Hanseníase do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo.

RESULTADOS - A maioria (63%) dos 49 doentes, não apresentou comprometimento da qualidade de vida, na aplicação do questionário Dermatology Life Quality Index. Quanto ao questionário genérico Short Form-36, os escores alcançados demonstraram pouco comprometimento da qualidade de vida.

CONCLUSÃO - O grupo de pacientes estudados com hanseníase paucibacilar mostrou pouco comprometimento da qualidade de vida levando-se em consideração os resultados obtidos nos dois questionários aplicados. Isto nos leva a concluir que quanto mais precoce é o diagnóstico e o tratamento, menor é o acometimento da qualidade de vida.

Palavras-chave: Dermatologia; Hanseníase; Qualidade de vida; Questionários

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INTRODUCTION

Leprosy is a chronic disease caused by the *Mycobacterium leprae*.¹ It affects primarily the peripheral nervous system and secondarily the skin. It can lead to deformities, sometimes irreversible, if not treated in time. For operational purposes, leprosy is nowadays classified into two major groups: paucibacillary (up to 5 lesions) and multibacillary (more than five lesions).²

Brazil is one of the countries with the highest rates of endemicity in the world, which determines the importance of this disease in terms of public health.

Besides the deformities, leprosy can, due to the associated stigma, still nowadays lead to attitudes of aversion and discrimination from society.

Aiming at improving the capacity building of the team involved with the patients' care and the therapeutic approach to many diseases, various questionnaires have been developed with the purpose of better understanding the reasons of eventual compromise of the quality of life.

In leprosy, as with other diseases, the most used instrument is the Short Form-36 (SF-36).

The Dermatology Life Quality Index (DLQI) is specific for dermatology, and is also used in other dermatoses besides leprosy.³

PATIENTS AND METHODS

The group of patients studied was classified according to the WHO (World Health Organization) criteria and adopted by the Sanitary Dermatology Technical Area as patients with paucibacillary leprosy. A total of 49 patients were interviewed, 16 males and 33 females.

Inclusion criteria:

1. Men and women older than 18 years of age.
2. Having the diagnosis of the disease for a period longer than 2 months, having been treated with at least two supervised doses of the specific therapy.
3. Paucibacillary group, except the pure neural form, which was not part of this work as there was no case in the studied group.

Exclusion criteria:

1. Patients with other important systemic diseases like: diabetes mellitus under systemic treatment, congestive heart failure, coronary insufficiency, peptic ulcer, hepatic or renal insufficiency.
2. Patients with other important cutaneous diseases like: hard to control atopic dermatitis, psoriasis, and vitiligo.
3. Patients who verbally refused to take part in the study.

The questionnaires applied were: the Dermatology Life Quality Index (DLQI) and the Short Form-36 (SF-36), without the comparative purpose,

but rather the ascertainment of the quality of life in different ways.

The Dermatology Life Quality Index (DLQI) consists of 10 multiple choice questions, and the scores are assessed in the following way: without compromise of the quality of life (0-1), with mild compromise (2-5), moderate (6-10), severe (11-20) or very severe (21-30).

Also used was the generic questionnaire Short Form-36 (SF-36), which consists of 36 items, distributed into 11 questions, which are part of two main components: the physical health component and the mental health component.⁴

The physical health component (PHC) encompasses four domains: functional capacity (FC), physical aspects (PA), pain (P) and overall health status (OHS).

The mental health component (MHC) encompasses four domains: vitality (V), social aspects (SA), emotional aspects (EA) and mental health (MH).

The SF-36 scores vary from zero to 100, where zero is considered the worst result and the 100 score the best one, which means, in the latter example, no compromise of the quality of life.

The calculations of each score, in the various domains, are done by previously determined formulas, and the results can be then depicted in the form of representative graphic figures.

RESULTS

From the 49 patients who took part in the study, all from the paucibacillary group, 33 (67,3%) were female and 16 (32,7%) male. In terms of the occurrence of reactional outbreaks, 41 patients (84%) did not have any episode and 8 patients (16%) had at least one reactional outbreak during the treatment.

The scores obtained from the Dermatology Life Quality Index (DLQI) questionnaires are depicted on graph 1, showing 63% of the patients without compromise of the quality of life, 15% with mild compromise, 10% moderate, 8% severe and 4% very severe.

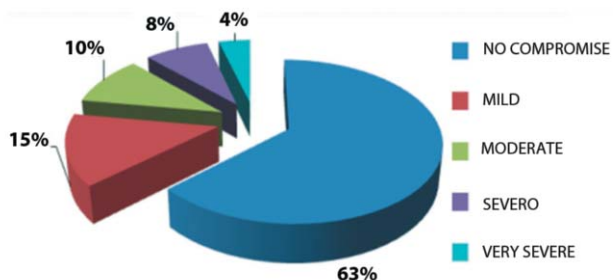
On the Short Form-36 (SF-36) questionnaire the calculation of the median was used for each of the eight domains, see graph 2, and the values of each domain are presented on table 1.

DISCUSSION

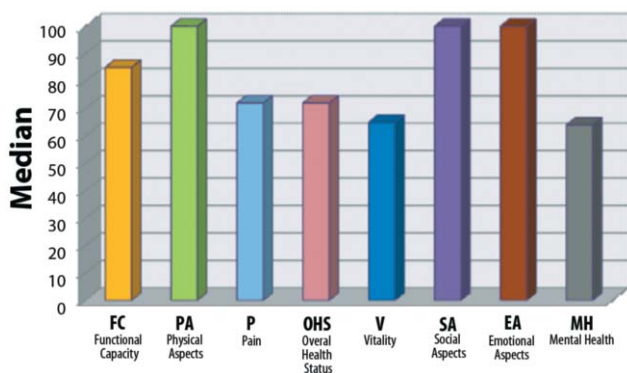
The patient with leprosy, if not treated, progresses with physical, psychological and social disabilities. Because of the stigma and the lack of knowledge in terms of the disease, the patients, sometimes, take a long time to seek adequate and specialized treatment, which culminates in impairment of their quality of life.

The visible deformities and the disabilities contribute to the stigmatization of the disease, both for

COMPROMISE OF THE QUALITY OF LIFE



GRAPH 1: Sample distribution according to the Dermatology life quality index



GRAPH 2: Comparison between the SF-36 domains

the patients undergoing treatment and the ones already cured.

On the other hand, even patients undergoing treatment might, during reactional outbreaks, present with deformities, sometimes permanent, if they are not adequately and timely treated. There is then a decline on the quality of life. However, if we consider well structured health programs, with early diagnosis and active case search we can observe a decrease or even an absence of sequelae related to the disease.

The patients who took part in this study were all from the paucibacillary group, therefore with less than five lesions and, as they were diagnosed and treated early, they also presented with a small number of sequelae.

The reactions were also less frequent in this group of patients studied.

The WHO (World Health Organization) defines quality of life as “ the individual’s perception in terms of their life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns “. ⁵

Despite the existence of leprosy for thousands

TABLE 1: Comparison among the SF-36 domains

| Domains | N. | Median |
|-----------------------|----|--------|
| Functional Capacity | 49 | 85 |
| Physical Aspects | 49 | 100 |
| Pain | 49 | 72 |
| Overall Health Status | 49 | 72 |
| Vitality | 49 | 65 |
| Social Aspects | 49 | 100 |
| Emotional Aspects | 49 | 100 |
| Mental Health | 49 | 64 |

of years, even nowadays there is discrimination in relation to the disease, mainly due to the visible deformities and to the fact that, in most cases, it affects people from low socio economic status, which also compromises the quality of life. ⁶

Many studies have been published regarding the quality of life in various dermatological diseases: atopic dermatitis, psoriasis. ⁷⁻¹¹

In Brazil and in other countries many studies have been published which analyzed the quality of life in leprosy, almost always assessing patients with advanced clinical forms of the disease, from both multibacillary and paucibacillary groups together. ¹²⁻¹⁵

In the present study the patients who answered the questionnaire had the paucibacillary form, with early diagnosis and treatment, therefore less prone to reactions and sequelae from the disease.

The instruments used in our work were: the generic Short Form-36 (SF-36) questionnaire, with 11 questions and a total of 36 items, which encompassed eight domains: four part of the physical health component (PHC): functional capacity (FC), physical aspects (PA), pain (P), overall health status (OHS) and four part of the mental health component (MHC): vitality (V), social aspects (SA), emotional aspects (EA) and mental health (MH).

The scores vary from 0 -100, where the zero is attributed to the worst result and 100 to the best, and as such, the zero score means accentuated compromise of the quality of life and the 100 score means no compromise of the quality of life.

When we analyze the median of the domains, we can observe that there are no significant differences among them, and all domains had a high score, demonstrating mild compromise of the quality of life in the group of patients studied.

The median with the lowest score was the mental health (64), followed by vitality (65), overall health status and pain (both with 72). Soon after comes the functional capacity with 85 and then, with 100 (no compromise), come the physical, social and emotional aspects.

Another instrument used was the “Dermatology

Life Quality Index" (DLQI), which is composed of ten questions, with multiple choice answers. The score varies from 0 -30, where 0 is attributed to the best result and 30 to the worst, namely: no compromise of the quality of life (0-1) or mild compromise (2-5), moderate (6-10), severe (11-20) or very severe (21-30).

In this questionnaire (DLQI), used in order to give more consistency to the results obtained with the SF-36, the results obtained were even more striking, where 63% of the 49 patients did not show any compromise of the quality of life, while only 37% had some level of compromise and only 4% had severe compromise.

This questionnaire is specific to dermatology and has been previously applied to other dermatological disease besides leprosy.

Therefore, overall we obtained favorable results, denoting mild compromise of the quality of life in the group of patients studied.

This is a descriptive work, and not comparative, keeping in mind that this is a small case series of patients from the paucibacillary group of the disease, and these results need to be ratified by subsequent studies with a bigger number of cases, in order to reinforce the idea that only with early diagnosis and

treatment can we improve the quality of life of patients with leprosy.

CONCLUSION

According to the results obtained in this sample, in contrast with those found on the literature published about the quality of life in leprosy, we can see that there have been no important changes in terms of quality of life of the patients who took part in the study.

From the 49 patients interviewed, 63% had no compromise of the quality of life, 15% a mild compromise, 10% moderate, 8% severe and 4% very severe (according to the DLQI).

All the domains of the SF-36 had a median over 64 and, from the 8 domains, 3 had a median of 100, there is, no compromise of the quality of life.

Maybe this is due to the early and precise diagnosis and immediate start of the specific treatment, when there was no time for the sequelae to develop, whether they are physical, social or psychological.

This work lead us to conclude that leprosy does not drastically compromises the quality of life if there is an effort towards early detection and treatment by the health sectors. □

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