

Comparison of quality of life questionnaires and their correlation with the clinical course of patients with psoriasis*

Comparação entre questionários de qualidade de vida e sua correlação com a evolução clínica de pacientes com psoríase

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Abstract: BACKGROUND: Psoriasis is a chronic inflammatory dermatosis characterized by erythematous, scaly lesions covering extensive areas of the skin and negatively affecting patients' quality of life by interfering in their personal life, social relationships and routine activities. Treatment offers reasonable control of the condition; however, little importance is generally given to the patient's impression.

OBJECTIVES: To evaluate the quality of life of patients with psoriasis, to verify whether there is a correlation between quality of life and clinical improvement and to compare two quality of life questionnaires and evaluate their equivalence.

METHODS: Patients over 18 years of age attending the psoriasis outpatient clinic at the Teaching Hospital of the University of Campinas (UNICAMP), who were either initiating treatment or changing to a new form of treatment, were included in the study. Patients answered two quality of life questionnaires (the Psoriasis Disability Index and the Dermatological Life Quality Index) up to a total of 180 consultations to evaluate whether there is a correlation between the questionnaires. Patients were also rated using a clinical index (Psoriasis Area and Severity Index) at baseline and at follow-up visits.

RESULTS: The study involved 138 patients (76 men; mean age 50 years). A correlation was found between the questionnaires and the clinical index, showing that clinical changes are reflected in quality of life. The two questionnaires were found to be equivalent.

CONCLUSION: It was found that both clinical condition and quality of life improved in the majority of patients receiving care at this outpatient clinic and that the quality of life questionnaires are equivalent.

Keywords: Psoriasis; Skin diseases; Treatment outcome

Resumo: FUNDAMENTO: A psoríase é uma dermatose inflamatória crônica caracterizada por lesões eritemato-desquamativas que atingem extensas áreas da pele, comprometendo a qualidade de vida dos pacientes por interferir na sua vida pessoal, no relacionamento social e nas atividades diárias. O tratamento permite um bom controle, mas a impressão do paciente, quase sempre, é pouco valorizada.

OBJETIVOS: Avaliar a qualidade de vida de pacientes psoriáticos, verificar se há correlação desta com melhoras clínicas e se há equivalência entre dois questionários de qualidade de vida.

MÉTODOS: Foram incluídos no estudo pacientes maiores de 18 anos que estavam no início ou troca de tratamento no ambulatório de psoríase do Hospital de Clínicas da Unicamp. Eles responderam dois questionários de qualidade de vida (Psoriasis Disability Index e Dermatological Life Quality Index), até completar 180 atendimentos, para avaliar se haveria correlação entre os questionários. Receberam também um índice clínico (Índice de Área e de Severidade da Psoríase) no tempo inicial da pesquisa e nos retornos subsequentes.

RESULTADOS: A pesquisa foi realizada com 138 pacientes (76 homens, idade média de 50 anos). Observou-se correlação entre os questionários aplicados e o índice clínico, mostrando que alterações clínicas se refletem na qualidade de vida, e que há equivalência entre os questionários.

CONCLUSÃO: Constatou-se que a maioria dos pacientes atendidos no ambulatório tem apresentado melhora clínica e da qualidade de vida e que há equivalência entre os questionários de qualidade de vida.

Palavras-chave: Dermatopatias; Psoríase; Resultado de tratamento

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Introduction

Patients with dermatological diseases, particularly chronic diseases, perceive their health as being affected, feel that the performance of their routine activities is limited and experience a loss of vitality, leading to the absences at school and work, in addition to depression and, in some cases, social isolation.

For example, psoriasis, in the majority of cases, does not cause physical damage to the same extent as chronic diseases such as hypertension or diabetes do; however it affects quality of life (QoL) as much as or even more than these diseases. Patients with psoriasis have a degree of limitations similar to that of patients with angina or hypertension; their physical and mental function is reduced to the same extent as that of patients with cancer, arthritis, hypertension, cardiac disease and depression. Furthermore, there is an association with psychiatric diseases including suicidal tendencies, with half of these patients expressing feelings of depression and anxiety with respect to their diagnosis.²

Psoriasis is a chronic, inflammatory, erythematous-squamous dermatosis with periods of exacerbation and remission. The term *psoriasis* comes from the Greek *psora* meaning "to itch" or an "eruption". The condition was first described by Celsus in the year 25 BC; however, it was confused with hanseniasis until 1809 when Robert Willan described its various clinical manifestations. For this reason, it is also known as Willan-Plumb syndrome.³

It is characterized by an uncontrolled proliferation of keratinocytes, complex changes in the differentiation of the epidermis and the attraction of T-cells to the skin. It has the characteristics of an autoimmune disease. Biochemical, immunological, inflammatory and vascular abnormalities are involved in the process.⁴

Its cause is unclear; however, various factors are known to trigger or exacerbate the condition, such as physical, chemical or surgical trauma, inflammation, infections, stress and certain drugs (lithium, beta-blockers, nonsteroidal antiinflammatory drugs, etc.).⁵ It is currently believed that even dietary habits may constitute important factors in the pathogenesis of this disease.⁶ Genetic disposition is a determining factor in the manifestation of the disease and has been extensively studied in recent years, relatives of patients with psoriasis having an increased risk of developing the disease.^{7,8}

Typical lesions are erythematous-squamous, clearly defined and covered with silvery-white, micaceous scales. They may be punctuated or follicular, lenticular or drop-shaped, nummular, annular, serpiginous plaques of differing sizes. Various forms may coexist in the same individual. They may be located at any site on the skin surface, including the mucosa

but are generally found at extensor sites such as the elbows, knees, the lumbar-sacral region and the scalp.³

Since the lesion is often stigmatized, information on the QoL of these patients is important, both for the doctor-patient relationship and for public awareness, in defining treatment and generating healthcare policies.² It is also a crucial factor in ensuring that the choice of therapy is not defined only on the basis of technical knowledge but is individualized so that the patient becomes involved in decisions regarding his/her treatment in an attempt to increase compliance with the proposed therapy.⁹

The treatment should be in accordance with the patient's needs and should incur the least possible risk to his/her health and QoL. Mild forms of the disease may be treated topically, while the more extensive forms, those resistant to treatment and the more severe forms such as the arthropathic, erythrodermic and pustular forms, require systemic treatment. Treatment should be alternated between the different therapeutical options in order to avoid tachyphylaxis and side effects over the long term.¹⁰ Nevertheless, the current forms of treatment for moderate to severe psoriasis are associated with toxicity in the short and long term, as well as patient dissatisfaction.¹¹

The Dermatology Life Quality Index (DLQI) and the Psoriasis Disability Index (PDI) were developed by investigators in the United States and validated for use in Brazilian Portuguese following authorization by the authors.¹²

The DLQI is a self-applicable questionnaire developed by Fynlay and Khan in 1994 as a simplified instrument to be used in clinical practice for application in patients with skin diseases.¹³ It consists of ten questions, each one with four possible answers and a score that ranges from 0 to 3 for each one (not at all/not relevant = 0; a little = 1; a lot = 2 and very much = 3).¹² This questionnaire evaluates symptoms and feelings (Questions 1 and 2), daily activities (Questions 3 and 4), leisure and sporting activities (Questions 5 and 6), work and school (Question 7), personal relationships (Questions 8 and 9) and treatment (Question 10), resulting in a final score that ranges from 0 to 30. This score can also be grouped in accordance with the impact on QoL (0-1 = no effect at all on patient's life; 2-5 = small effect; 6-10 = moderate effect; 11-20 = very large effect; and 21-30 = extremely large effect on patient's life).^{13,14}

The PDI is an instrument used to evaluate the QoL of patients with psoriasis, in which indicators of the impact of the disease on lifestyle and daily routine in specific areas are measured.¹⁵ It consists of 15 questions divided into: daily activities (Questions 1-5), school or work (Questions 6-8), personal relation-

ships (Questions 9-10) and leisure (Questions 11-15). Each question has four possible answers, receiving a score of 0 to 3 (not at all = 0; a little = 1; a lot = 2; very much = 3), resulting in a final score that ranges from 0 to 45.

Clinical data on the extent of the disease were obtained using the Psoriasis Area and Severity Index (PASI), applied during consultation with the physician, for the purpose of obtaining an objective impression of the patient's current clinical status.¹³ Data are collected on the most important clinical variables in psoriasis (the area affected, erythema, infiltration and desquamation), which are evaluated in accordance with the region affected (head, trunk, upper or lower limbs). The area is evaluated in accordance with the percentage of the body area affected and transformed into a score that ranges from 0 (0% of the area affected) to 6 (90-100% of the area affected). Erythema, infiltration and desquamation are evaluated in accordance with the severity of these clinical features, and are awarded a score of 0-4 depending on whether the feature is absent (0), mild (1), moderate (2), severe (3) or very severe (4), resulting in a final index that, theoretically, may range from 0 to 72.^{16,17}

Studies indicate that, although there is no correlation between the absolute values of the PASI and DLQI questionnaires, significant reductions in the PASI are associated with an improvement in QoL (DLQI).¹⁸

The objectives of the present study were to evaluate the QoL of patients with psoriasis, to verify whether there is a correlation between QoL and clinical improvements, and to evaluate whether the two QoL questionnaires (DLQI and PDI) are equivalent.

Material and Methods

A prospective study was conducted to evaluate patients receiving care at the psoriasis clinic of the Dermatology Department at the University of Campinas (UNICAMP) Teaching Hospital. Data collection began in February 2006 and finished in February 2009.

Patients over 18 years of age with a diagnosis of psoriasis, who were initiating treatment with topic or systemic medication for control of the condition or were in the process of changing from one therapeutic regimen to another, were included in the study.

The PASI questionnaire was applied by a physician during a medical consultation. Evaluation of the patient's QoL was made by a second investigator on the same day, immediately after the first consultation. The same process was repeated at return visits.

To test the equivalence of the QoL questionnaires, they were applied at 180 consultations. If the two questionnaires were found to be equivalent, then only the questionnaire that was simplest to apply

would be used for the remainder of the study period.

The charts of the patients who returned to the clinic at least once after the baseline visit were evaluated, including data on compliance with treatment, the form of treatment, the period of use of the medication, other diseases, assiduity in attending consultations, improvement or deterioration in the patient's clinical status or quality of life, and side effects.

The data were analyzed using the SPSS statistical software program, version 16.0 (SPSS Inc., Chicago, Illinois, USA). The mean, standard deviation, range and quartiles were determined for age (years), time (days) and PDI, DLQI and PASI scores. Spearman's correlation coefficient was used to assess the association between the PDI, PASI and DLQI questionnaires. Significance level was defined as 5%.

The project was approved by the Internal Review Board of the School of Medical Sciences, UNICAMP. The patients invited to participate in the study were only included after they had read and signed the informed consent form.

Results

A total of 148 patients were included in the study, resulting in the completion of 313 valid questionnaires, 148 of which were filled out at baseline/time-point 0 (1st consultation), 86 at time-point 1 (1st follow-up visit), 51 at time-point 2 (2nd follow-up visit) and 28 questionnaires at time-point 3 (3rd follow-up visit). Of the patients studied, 76 were male and 62 female; 114 white, 20 brown and 4 black.

At the time of the final evaluation, patients' age ranged from 19 to 81 years, with a median of 53.5 years. The time between completing the first and second questionnaires (baseline to time-point 1) ranged from 35 to 848 days (median 154 days), while the time between time-points 1 and 2 ranged from 35 to 658 days (median 189 days) and the time between time-points 2 and 3 ranged from 35 to 553 days (median 224 days). The distribution of these data is shown in Table 1.

Distribution of the DLQI, PDI and PASI scores are shown in Table 2 and Figure 1. A correlation was found between the PASI and PDI scores, between the DLQI and PDI scores and between the PASI and DLQI values. Spearman's correlation coefficients are shown in Table 3.

Discussion

Cross-analysis of the questionnaires (Spearman's correlation coefficient) showed that the means obtained in the PDI and DLQI were strongly correlated. This was expected, considering that, although the first questionnaire is specific whereas the second is generic, both deal with the QoL of patients with dermatological lesions, in this particular case

TABLE 1: Distribution of patients according to age at the end of the study and time between return visits

	n	Mean	SD	Min.	1 st Quartile	Median	3 rd Quartile	Max.
Age (years)	148	51.1	15.3	19	41.0	53.5	62.9	81
Time 1 (1)	86	218.0	186.1	35	84.0	154.0	274.7	848
Time 2 (2)	51	217.0	140.8	35	91.0	189.0	301.0	658
Time 3 (3)	28	230.25	148.4	35	113.7	224.0	320.2	553

n = number of cases;

(1) = time (in days) until 1st return visit;

(2) = time (in days) between 1st and 2nd return visits;

(3) = time (in days) between 2nd and 3rd return visits;

psoriasis. The closer to 1 the result of Spearman's test, the higher the correlation between the questionnaires, 1 being the coefficient obtained when the relevant questionnaires are identical. Therefore, the correlation between these two questionnaires was found to be so high that the results found by one barely differed from those found with the other, i.e. they are practically equivalent. In view of this finding, it was agreed that it would be feasible to use only one of these questionnaires to evaluate the QoL of these patients without any detriment. The questionnaire selected was the DLQI, since it is simpler and faster to complete (with respect to the language used and the number of questions).

A correlation was found between QoL and clinical index, showing that clinical improvements are reflected in an improvement in the effect of the disease on QoL and vice-versa.

In the final result, a significant improvement was found in the scores of the patients who returned to the clinic, a strong indication that the treatment

was effective. A great improvement was seen at the first follow-up visit, probably due to the effect of having initiated treatment, together with the psychological factor triggered by this fact. At the second return visit, there was little difference in the mean scores; in fact, they were practically the same as those registered at the first follow-up visit. However, when cases were evaluated individually, the moderate improvement found in some patients was found to have been offset by a moderate deterioration in others. This may be due to the end of the initial impact of treatment (end of the psychological effect), since medication takes some time to exert an effect that would effectively be reflected in the symptomatology and to stabilize or improve the lesions, leading to a certain degree of disappointment and difficulty in achieving appropriate compliance with treatment. At the third follow-up visit, an improvement is once again evident, probably due to the prolonged and continuous action of the medication.

Treatment progression tends to remain the

TABLE 2: Distribution of patients according to PASI and DLQI scores throughout the study

	n	Mean	SD	Min.	1 st quartile	Median	3 rd quartile	Max.
Baseline								
PASI	148	12.5	10.6	0	4.8	10.5	17.0	57.0
DLQI	148	5.6	4.5	0	2.0	5.0	8.0	26.0
1st return visit								
PASI	86	8.5	8.0	0	2.4	5.8	12.2	36.4
DLQI	86	2.9	3.1	0	1.0	2.0	5.0	14.0
2nd return visit								
PASI	51	10.0	10.4	0	3.0	7.2	12.6	45.0
DLQI	51	3.1	4.0	0	0.5	2.0	3.5	15.0
3rd return visit								
PASI	28	10.5	10.7	0	2.4	6.4	17.9	43.6
DLQI	28	3.7	3.9	0	1.0	2.0	6.5	13.0

n – number of cases;

SD: standard deviation;

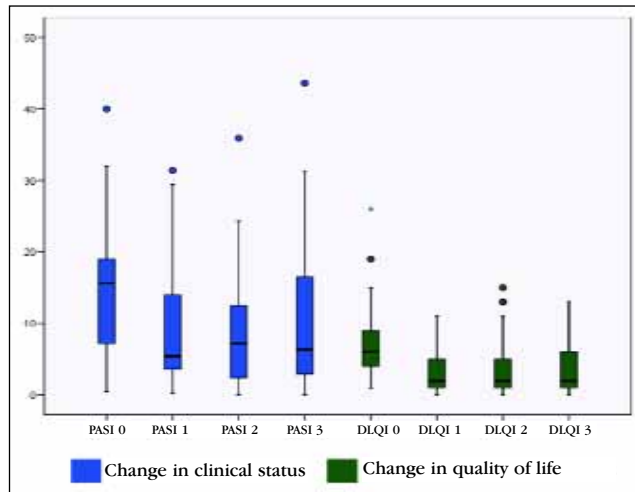


FIGURE 1: Changes in clinical status and quality of life at the four time-points in the study

same irrespective of the therapeutic options used (a substantial improvement at the first return visit followed by stabilization or a slight deterioration at the second return visit and further improvement at the third), which may be a consequence not only of a psychological factor but also to the pattern of response to the medication.

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TABLE 3: Spearman's correlation coefficient for the PASI, PDI and DLQI

	PASI	DLQI
Baseline		
PASI (n= 138)	1.000	0.423*
PDI (n= 112)	0.416*	0.787*
1st return visit		
PASI (n= 82)	1.000	0.531*
PDI (n= 53)	0.401*	0.606*
2nd return visit		
PASI (n= 43)	1.000	0.448*
PDI (n= 15)	0.323*	0.775*

(*) – $p < 0,05$

Conclusion

An improvement was found in the clinical condition and quality of life of the majority of patients receiving care at this clinic. Since the two questionnaires were found to be equivalent, the DLQI then began to be used alone in the routine of the psoriasis clinic at UNICAMPs Teaching Hospital, both for research purposes and for initial assessment and follow-up of the patients. □

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