

Impact of dermatological diseases on family members of the patients using Family Dermatology Life Quality Index: A preliminary study in Iran

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Background: Chronic skin diseases such as vitiligo and psoriasis can impair the quality of life in the patients with these diseases. The impact of chronic and/or severe skin diseases on the lives of family members of the affected patients has only recently been addressed. The tool used for this assessment is the Family Dermatology Life Quality Index (FDLQI). The aim of this study was to use the FDLQI to assess the impact of four skin diseases (pemphigus, psoriasis, vitiligo, and cutaneous leishmaniasis) on family members of the affected patients.

Method: Fifty healthy family members of 50 patients with pemphigus, psoriasis, vitiligo, and cutaneous leishmaniasis were included in this study. The patients had to have an extensive disease with disease duration of at least one month. One family member of each patient completed the 10- item Persian version of the FDLQI questionnaire. The score of this index ranged from 0 to 30.

Result: The mean duration and mean FDLQI score of the diseases were as follows: psoriasis (mean duration=4.1±2.7, mean FDLQI score=14.7±5.01), pemphigus (mean duration=3.6±2.3, mean FDLQI score=15.4±4.7), vitiligo (mean duration=5.1±4.05, mean FDLQI score=14.4±5.08) and cutaneous leishmaniasis (mean duration=0.62±0.23, mean FDLQI score=12.0±4.3). There was no significant difference among the groups (p=0.562). In addition, no strong correlation was observed between the mean duration of the disease and mean FDLQI scores for each condition (r=0.051, p=0.726).

Conclusion: This small-scale study demonstrated that although not statistically significant, inflammatory diseases like pemphigus had a higher FDLQI score when compared to non-inflammatory conditions like vitiligo and short-term conditions such as leishmaniasis.

Keywords: cutaneous leishmaniasis, family dermatology life quality index, quality of life, pemphigus, psoriasis, skin disease, vitiligo

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INTRODUCTION

Dermatologic diseases, especially chronic ones such as psoriasis, can have serious impacts such

as cost of illness on the patients' quality of life as well as their partners or close relatives, and are comparable to other chronic medical disorders ^{1,2}. Also, based on recent studies, skin diseases such

as vitiligo and epidermolysis bullosa significantly affect both the patient and his/her family members' quality of life (stigmatization, nasty comments or distress)^{3,4}.

A study by Basra et al⁵ showed that many aspects of the family members' lives of the patients can be impaired such as social, financial or health issues. The Family Dermatology Life Quality Index (FDLQI) is a 10- item questionnaire, aimed at measuring the impact of dermatological diseases on the families of the patients with skin diseases. This index was validated in the aforementioned study. This questionnaire measures the following issues: emotional distress, increased household expenditures, social life, relationships, others' reactions to the disease, physical well-being, recreation, taking care of the patient, housework, and job^{5,6}. This index was further validated in 2008, compared to an index named "impact on family scale"⁷. We decided to measure the Family Dermatology Life Quality Index (the validated Persian version⁸) to identify major issues that affect the quality of life of the family members or partners of the patients with chronic and severe skin diseases in an Iranian population.

PATIENTS AND METHODS

Fifty healthy family members (adult and first degree or partners of 50 patients with pemphigus, psoriasis, vitiligo, and cutaneous leishmaniasis) were included in this study. We decided to conduct our study on 50 participants in accordance with the study performed by Basra et al⁵. The study was undertaken at the Dermatology Department of Faghihi Hospital, Shiraz, Iran, in 2013. Convenient sampling was used to recruit the family member of each patient and the patients had to have an extensive disease with disease duration of at least one month. Each family member was asked to complete the 10- item validated Persian version of the FDLQI questionnaire after receiving detailed explanation the objectives of the study and giving their consent. The score ranged from 0 to 30. A higher the score indicated more impairment.

The scoring method for each question was as follows:

- Not at all: 0
- A little: 1
- Quite a lot: 2

Very much: 3

Question unanswered: 0

The relationship with the patient, the disease diagnosis, and the duration of the disease as well as the FDLQI score (sum of the scores) were documented in each questionnaire. All family members of the patients completed the questionnaire. SPSS version 18 was used for data analysis. The difference between the mean scores of the four groups was assessed using univariate analysis of variance. Also, we used the Pearson's correlation coefficient to evaluate the relationship between the FDLQI scores and the duration of the disease. In all analyses, $P < 0.05$ was considered significant.

RESULTS

The participants in our study were 27 females (54%) and 23 males (46%) with an age range of 20 to 65 years (mean age=42). Thirty- two percent of the cases were partners of the patients and 68% were first degree relatives (parents, siblings).

The mean FDLQI scores and the mean duration of the conditions were shown in table 1. There was no significant difference between the mean scores of all four groups (P value=0.562). Also, there was no strong correlation between the mean duration of the diseases and the mean FDLQI scores ($r=0.051$, P value=0.726). The main complaints of family members were shown in table 2.

DISCUSSION

The quality of life of the family members and partners of vitiligo patients ($n=129$) was assessed in a study by Bin Saif et al³. The mean FDLQ score was 10.3 and higher scores were observed in male family members with a recent disease onset and highly educated family members. The main problems mentioned were emotional distress, spending extra time for the patient, and reactions of the others to the patient's condition. It was concluded that vitiligo could significantly impair the quality of life of the family members of the patients. In our study, a higher FDLQI score was seen in the family members of vitiligo patients (14.4) compared to the results reported by Bin Saif et al, but similar to their study, emotional distress (53.3%) was one of the most frequent concerns among the family

Table 1. The mean FDLQI scores and the mean duration of the conditions

Disease	Mean FDLQI score	Mean duration	N
Psoriasis	14.70 ± 5.01	4.1 ± 2.7	10
Pemphigus	15.45 ± 4.70	3.6 ± 2.3	20
Vitiligo	14.40 ± 5.08	5.1 ± 4.05	15
Leishmaniasis	12.00 ± 4.80	0.62 ± 0.23	5

members. Eghlileb et al¹ evaluated the impact of psoriasis on family members of psoriatic patients (n=63) and compared it with the quality of life of the patients. There was a strong correlation between these two qualities (r=0.77, P<0.001) and the quality of life of the family members was significantly affected (some high scores were also seen in our study). The family members' main concerns were anxiety, feeling worried about the patient's future, and some limitations in recreational activities and hobbies (similar to our study in which emotional distress was the most frequent concern). In another study by Eghlileb et al⁹ in 2009, the Psoriasis Family Index was validated. A moderate to strong correlation was seen between the Psoriasis Family Index and the Dermatology Life Quality Index scores (r=0.54, P<0.01). Again, it was shown that psoriasis had a major impact on the quality of life of the family members of the patients. In another study by Basra et al⁵ in 2007, fifty family members of patients (21 dermatological diseases) were asked about fifty nine aspects of the quality of life. Emotional upset, burden of care, and social life impairment were among the most common concerns of the family members with no significant difference between male and female subjects. It was concluded that different dermatological diseases could have a strong deteriorating impact on family members' quality of life; therefore, it is necessary to investigate this issue in the general evaluation of dermatological patients. Basra et al⁶ assessed the quality of life of 132 family members and compared it with the Dermatology Life Quality

Index in 109 patients. A strong correlation (r=0.69) was observed between the two groups. Higher FDLQI scores were documented in inflammatory skin diseases as compared to non-inflammatory skin diseases (P<0.0001). These results are similar to our study in which pemphigus (inflammatory diseases) had higher FDLQI scores when compared to vitiligo (non-inflammatory) (15.4 vs. 14.4). Also, a positive relationship was seen between the FDLQI scores and disease severity (r = 0.49). So, it was concluded that this index was helpful and practical in measuring the adverse impacts of skin diseases on the quality of life of the family members of the patients.

In a study on 62 family members of patients with epidermolysis bullosa (using the Italian version of the FDLQI), the mean FDLQI was 9.8. The scores were higher in the families with a 10- to 20-year-old patient⁴. The problems most frequently mentioned by family members of these patients were as follows: spending a lot of time taking care of the patient, emotional upset, and increased expenditure.

Atopic dermatitis can impair the quality of life of both patients and their family members. The scores measured using the Infant's Dermatitis Quality of Life Index and the Dermatitis Family Impact Questionnaire were rather similar¹⁰. In another study on atopic dermatitis, the child's age was correlated with the emotional distress of the parents, with an impact on relationships in the families with affected girls. Also, the patient's gender was proposed as a strong factor in the family's quality of life¹¹.

This small scale study demonstrated that chronic and severe skin diseases could make some problems for the family members of the patients. Inflammatory diseases like psoriasis had a higher FDLQI score compared to non-inflammatory conditions like vitiligo and short-term conditions such as leishmaniasis. This fact

Table 2. The main complaints of family members

Disease	Most complaints by partners or relatives	Percentage of members
Psoriasis	Emotional distress	50%
	Looking after patient	35%
Pemphigus	Increased routine household expenditure	60%
	People's reaction to disease	40%
Vitiligo	Emotional distress	53.3%
	Impaired social life	33.3%
Leishmaniasis	Time spent looking after partner or relative	40%

needs to be addressed in the overall general care and management of these patients and appropriate psychological support should be given to some of these family members. Larger studies are needed to confirm these preliminary results with including more skin diseases.

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