

# Evaluation of quality of life in parents of the patients with vitiligo by Persian version of the family dermatology life quality index (FDLQI) in Kerman

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## Abstract

**Background** Vitiligo can have negative effects on different aspects of life of the patients and their families including financial and occupational issues, social relationship and selection of leisure time activities. In this study for the first time in Iran we evaluated effects of vitiligo on family members of the patients.

**Material and Methods** We performed a cross sectional study on 150 of family members of the patients with vitiligo in Afzalipour hospital in Kerman. Family Dermatology Life Quality Index (FDLQI) questionnaire was used for measuring quality of life. FDLQI questionnaire was completed by family members of the patients. Data were analyzed with SPSS 18(SPSS Statistics, IBM, Armonk, NY, USA). We used Pearson correlation test, t-Test and ANOVA for analysis.

**Results** Mean age of the family members was 41.2 years and most of the responders were female (73.3%). Mean score of FDLQI was  $6.1 \pm 6.1$ . The highest scores belonged to psychosocial and financial effects. The lowest scores belonged to questions about occupational and educational issues.

**Conclusion** There was a reverse correlation between family dermatology life quality index and patient's age. Parents and children of the patients with atopic dermatitis had the worst and best quality of life, respectively.

## Key words

Quality of life, vitiligo, Persian, family.

## Introduction

Vitiligo is a chronic pigmentary skin disease with prevalence rate of nearly 0.5 to 2% in the world.<sup>1</sup> The most common type of the disease is vulgaris that is clinically determined by scattered, depigmented macules and patches

with distinctive border. Pathogenesis of the disease is not known and there is no definite treatment for the disease.<sup>2</sup> Vitiligo can lead to psychological effects such as depression, anxiety, frustration and low self confidence in patients and can eventually lead to social isolation and impaired quality of life (QoL).<sup>3,4</sup>

It may lead to limitation in physical activities such as sport and leisure activities due to the development of new lesions at sites of trauma (Koebner effect). Furthermore, tendency to cover the lesions affects the dressing and

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lifestyle patterns. Chronicity of the disease and long-term treatment leads to a lot of time and cost requirements for frequent physician visits and phototherapy sessions.<sup>5-7</sup>

Based on previous studies, lower QoL is reported in patients who had longer duration and more widespread disease, darker skin types, female gender with involvement of visible sites.<sup>8-11</sup> On the other hand, vitiligo can have negative financial and occupational effects on family members including social relationship and selection of leisure activities.<sup>12-15</sup>

In this study for the first time in Iran we decided to evaluate effects of vitiligo on family members of the patients.

## **Material and Methods**

We performed this cross sectional study on 150 family members of the patients with vitiligo in Afzalipour hospital in Kerman. After signing the written consent form by family members older than 18 years of age and living in the same place with the patients who were able to read and understand Persian language were enrolled in study. We recorded demographic features of the patients including age, sex, job and educational level, clinical characteristics of the lesions (type of vitiligo, site, duration and percentage of involvement). Demographic features of family members including age, sex, job, educational level and familial relation with the patients were recorded. Then, we asked family members to complete FDLQI questionnaire. Validity and reliability of Persian version of the questionnaire was previously approved (Cronbach's alpha =0.87).<sup>15</sup> It consists of 10 questions about how disease affected on different aspects of the family member's life since last month. Questions assess physical and psychological condition, inter-personal and social relationship, educational, occupational and leisure activities.

Each question has 4 answers scored from 0 to 3. Final score is determined by sum of all scores ranging 0 to 30. The greater score has the more effect on QoL of family members.

## **Statistical analysis**

We used SPSS 18 (SPSS Statistics, IBM, Armonk, NY, USA) to analyze data for descriptive analysis; we used frequency and percentages, mean±SD, standard deviation and central tendency. For analytic test; we used t-Test, ANOVA and Pearson correlation test. P. value less than 0.05 was considered significant.

## **Results**

One hundred and fifty family members were enrolled in the study. Mean age of the patients and family members were 30.7 (ranged 6-72) and 41.2 (ranged 18-73), respectively. **Tables 1-3** show demographic features of the patients and their family members and clinical characteristic of the lesions.

### *FDLQI questionnaire*

Mean score of FDLQI was 6.1±6.1 (ranged 0-24, median 5). The highest scores belonged to question number 1 (psychosocial effect) and 10 (financial effect). The lowest scores belonged to question number 9 (occupational and educational issues) and 6 (leisure activities) (**Table 4**).

Correlation between FDLQI and demographic features of the patients:

There was no significant correlation between FDLQ scores and sex of the patients. There was a significant and inverse correlation between patients' age and QoL scores (**Table 5**).

- Correlation between FDLQI and clinical features of the lesions:

**Table 1** Demographic features of patients with vitiligo

Characteristics		Prevalence (%)
Sex	Male	69(46)
	Female	81(54)
Job	Private	28(18.7)
	Employee	31(20.7)
	Worker	4(2.7)
	Housekeeper	31(20.7)
	Other	56(37.3)
Education	College diploma	40(26.7)
	BS	97(64.6)
	MS	2(1.3)

**Table 2** Clinical features of vitiligo lesions in patients

Characteristic		Prevalence (%)
Type of vitiligo	Focal	51(34)
	Segmental	3(2)
	Vulgaris	77(51.33)
	Mix	13(8.67)
	Acrofacial	6(4)
Location	Head & face	83(55.3)
	Neck	18(12)
	Upper limb	18(12)
	Lower limb	13(8.7)
	Trunk	18(12)
Duration of the disease	≤1 year	45(30)
	2-5 year	54(36)
	6-10 years	22(14.7)
	≥10 years	29(19.3)
Percentage of the involvement	≤1	88(58.7)
	2-5	42(28)
	≥5	20(13.3)

**Table 3** Demographic features of family members of the patients

Characteristics		Prevalence (%)
Sex	Male	40(26.7)
	Female	110(73.3)
Job	Private	29(19.3)
	Employee	25(16.7)
	Worker	1(0.7)
	Housekeeper	81(54.0)
	Other	14(9.3)
Education	College diploma	15(10)
	BS	108(72)
	MS	27(18)
Relationship	Parents	59(39.3)
	Spouse	62(41.3)
	Sibling	14(9.3)
	Children	10(6.7)
	Other	5(3.3)

There was no significant correlation between FDLQ score and clinical characteristic of the

lesions including percentage, duration and site of involvement (**Table 5**).

- Correlation between FDLQI and demographic features of family members:

There was no significant correlation between FDLQI and demographic features (age, sex, educational level and job) of family members (**Table 5**).

- Correlation between FDLQI and type of relationship between family members and the patient:

There was a positive and significant correlation between FDLQI and type of relationship between family members and the patient. The highest and lowest FDLQ scores were achieved by parents and children of the patients, respectively (**Table 5**).

## Discussion

Dermatologic diseases such as vitiligo may lead to impaired QoL of patients and their family members due to chronicity and need for long-term treatment.

Financial load (Expensive treatment modalities, frequent phototherapy sessions and physician visits) may have a profound effect on the family. On the other hand, wrong believes such as contagiousness of the disease and similarity to leprosy can lead to social-isolation of patients and have a negative impact on social relationship of family members as well. Furthermore, development of the lesions after physical injury (koebner effect) and more visibility of them after sun-exposure can influence leisure and sport activities of the family.<sup>16-19</sup>

**Table 4** Mean scores of items of FDLQI and percentage of answer of each question

No.	Items	Mean ±SD	Not at all	A little	Quite a lot	Very much
1	Emotional impact	0.98±1.03	42	30.7	14.7	12.7
2	Physical well-being	0.75±0.83	46.7	34.7	15.3	3.3
3	Relationship	0.51±0.74	61.3	28.7	7.3	2.7
4	People's reaction	0.67±0.80	52.7	28.7	17.3	1.3
5	Social life	0.52±0.74	60.7	28.0	9.3	2
6	Leisure activities	0.45±0.72	66	25.3	6	2.7
7	Burden of care	0.63±0.81	56	26.7	15.3	2
8	Housework	0.44±0.69	66.7	23.3	9.3	0.7
9	Job/study	0.32±0.61	75.3	16.7	8.0	0
10	Financial burden	0.80±0.884	45.3	31.3	21.3	2

**Table 5** FDLQI scores based on demographic features

Characteristics	Number	Mean ±SD	P. Value
Patients age	≤20	37	8.2±6.9
	21-30	41	6.5±6.1
	31-40	39	4.8±5.2
	>40	33	4.5±5.7
Family member ages	≤30	34	4.9±6.3
	31-40	49	6.6±5.9
	41-50	33	6.2±6.8
	>50	34	6.3±5.8
Patients sex	Male	44	8.3±4.6
	Female	60	9.1±6.2
Family sex	Male	28	8.1±6.4
	Female	76	9.02±5.2
Family education	College diploma	15	6.6±5.5
	BS	108	5.9±6.8
	MS	27	5.2±5.07
Relationship	Parents	59	8.0±6.5
	Spouse	62	5.3±5.9
	Sibling	14	3.7±4.5
	Children	10	3.2±4.8
	Others	5	5.8±5.9
Family job	private	29	5.6±5.9
	Employee	25	5.5±6.2
	Housekeeper	81	6.5±6.0
	Other	14	4.5±6.7
Site of involvement	Head & face	83	7.08±7.2
	Neck	18	9.4±3.1
	Upper limb	18	5.4±7.09
	Lower limb	13	5.3±4.5
	trunk	18	5.5±11.0
Duration of disease	≤1 year	45	5.8±6.1
	2-5 year	54	5.3±6.1
	6-10 years	22	7.4±6.3
	≥10 years	29	7.0±6.2
Percentage of the involvement	≤1	88	6.3±6.01
	2-5	42	5.2±6.06
	≥5	20	6.7±7.3

Currently, evaluation of quality of life of family members of the patients with diseases such as psoriasis, atopic dermatitis, porphyria, epidermolysis bollousa, pemphigus, vitiligo and leishmaniasis have been performed in deferent countries.<sup>20-26</sup> The most evaluated disease is atopic dermatitis and the least quality of life belonged to patients with pemphigus. According to our knowledge, this study is the first study in Iran and the second in the world that has evaluated FDLQI in family members of the patients with vitiligo. Mean score of FDLQ in this study was  $6.1 \pm 6.1$ . In one study in Saudi Arabia by Bin Saif and colleagues this score was estimated  $10.3 \pm 6.4$ . So, family members of our patients have higher quality of life than Saudi Arabia. This may be explained by difference in cultural issues and percentage and site of involvement between the 2 studies.

In Saudi Arabia study, patients with shorter duration of the disease, male gender and higher educational level had more impaired QoL in family members.<sup>17</sup> In the present study there was no significant correlation between FDLQI and demographic features of the patients and family members, except an inverse correlation with age of the patients. Family members of the patients with age less than 30 years have lower FDLQI than older ones. A possible explanation for this can be due to more prevalence of depression, mood disorders as well as more facing of these age groups to social issues such as problems in marriage and getting a job that can influence QoL of the family members as well.<sup>3-5</sup>

In the current study, there was no meaningful correlation between percentage of involvement and FDLQI. Furthermore, this indicates that even development of a small lesion can cause considerable concern and stress in other family members. Currently, there is no study to assess correlation between percentage of involvement and FDLQI in family members of vitiligo

patients, but in the studies on AD and psoriasis patients, there is a positive relationship between severity of the disease and FDLQI scores. This contrast owing to receiving systemic therapies such as immunosuppressive and biologic drugs to control widespread disease in AD and psoriasis patients that can lead to more side effects and spending a lot of money for the treatment. So higher FDLQI scores following to increase in severity of these diseases is expectable.<sup>21,22,25,26</sup>

In our study, the most items that lead to impaired QoL of the family members were psychosocial (question 1) and financial (question 10) issues. Occupational and educational issues (question 9) and housework burden (question 8) had lower impacts on QoL of the family members. In Saudi Arabia study, psychosocial issues (question 1) and burden of care (question 7) had considerable influence on FDLQI. The house work burden (question 8), job and educational issues (question 9) had the slightest effect on FDLQI.<sup>17</sup> Treatment cost in our study was the second factor that has impact on FDLQI, but in Saudi Arabia it was the 7<sup>th</sup> factor.<sup>17</sup> This disparity can be due to the difference in insurance policy and socioeconomic levels of the 2 studies.

In the present study, parents of the patients had the lower QoL comparing to other relatives of the patients. This can be due to more concern of the parents about the effects of the disease on future of their children. In Saudi Arabia study, children and subsequently spouse of the patients had the lowest QoL among the family members. This can be due to cultural diversity between these 2 countries.

Salsberg in one study demonstrated that covering of skin lesions with cosmetic camouflage have a considerable effect in improvement of QoL of patients with

dermatologic disease and their family members.<sup>19</sup> This result proves the importance of physical appearance of dermatologic disease on QoL of the patients and their families. In conclusion special attention to emotional stress and psychosocial problems in vitiligo patients and their family members should be an essential component of treatment protocol of the patients, as well as psychiatrist consultation and supportive methods such as group therapy.

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