Stigma Experience in Patients With Vitiligo: A Comprehensive Study in a Skin Hospital

Ali Zare Dehnavi[1], Maryam Daneshpazhooh[1], Abbas Dehghani[1], Kamran Balighi[1], Arghavan Azizpour[1], Mehdi Yaseri[2], Seyed Mohammad Seyed Ebrahimi[1], Hamidreza Mahmoudi[1]

[1] *Autoimmune Bullous Diseases Research Center, Tehran University of Medical Sciences, Tehran, Iran*

[2] *Department of Epidemiology and Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran*

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Abstract- Vitiligo is the most common cause of skin depigmentation, which relates to a wide range of psychological disorders. Stigma is defined as a negative attitude towards oneself that results from one's perception of being different from the general population. In this study, we have evaluated the quality of life and stigmatization degree among vitiligo patients. In this cross-sectional study, 323 patients with vitiligo referred to Razi Hospital, Tehran, Iran, were evaluated. All patients were asked to fill out a questionnaire containing age, gender, marital status, educational level, employment status, duration of vitiligo, location of lesions, history of underlying diseases, history of previous treatments, as well as history of depression or suicide. Quality of life and stigmatization among patients were assessed by DLQI (dermatology life quality index) and FSQ (feeling stigmatization questionnaire) questionnaires. The prevalence of moderate and severe stigmatization were 49.8 % and 13.3%, respectively. Women were significantly more stigmatized than men. The presence of vitiligo lesions on the face, hands, or forearms, previous topical and oral treatments, and prior depressive disorders were significantly associated with an increased sense of stigma. Patients with thigh or trunk lesions faced less stigmatization. Additionally, stigmatization was meaningfully related to the level of quality of life impairment. In the present study, 63% of patients with vitiligo experienced moderate to severe stigmatization levels related to gender, lesion site, history of prior treatments, and depression. Moreover, there was a significant correlation between the level of stigma sensation and the life quality disturbance.

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Introduction

Vitiligo is the most common cause of skin discoloration, with prevalence varying between 0.1 and 2% (for both children and adults) (1,2). Both sexes are equally affected by the disease, and there is no significant difference in the prevalence of the disease between different races or socioeconomic classes (3).

The etiology of vitiligo remains unclear, but patients usually attribute its occurrence to several factors, including physical trauma, inflammation, illness, sunburn, stress, or pregnancy (3). There are many hypotheses for the destruction of melanocytes in vitiligo, including genetics, autoimmunity, neural, biochemical, oxidative stress, viral infection, and melanocyte detachment mechanisms. Although autoimmunity and oxidative stress theories are supported by more evidence (4,5), they alone cannot explain vitiligo types. Genetic studies have shown that vitiligo inheritance is non-Mendelian, multifactorial, and polygenic (6,7). According to studies, up to 50 percent of vitiligo patients have relatives with the disease, and in 6 percent of cases, the patient's sibling is infected (8).

Each patient’s strategy and therapeutic goals are explicitly determined according to various factors such as the patient's age, skin type, the extent of skin

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Corresponding Author: H. Mahmoudi
Autoimmune Bullous Diseases Research Center, Tehran University of Medical Sciences, Tehran, Iran
Tel: +98 2155618989, Fax: +98 2155618989, E-mail address: hr_mahmoody@yahoo.com

involvement, location of lesions, the severity of the disease, and impact of the disease on the patient's quality of life. Meanwhile, discussing treatment limitations with patients and establishing realistic expectations of existing treatments is beneficial.

Several treatments are available for vitiligo, including topical and oral corticosteroids, calcineurin inhibitors, phototherapy, and autologous grafting.8 Combined therapies, such as phototherapy and topical or oral treatments, have been more effective than single therapies (9). Although vitiligo is broadly regarded as an aesthetic problem, it can adversely affect patients' mental health and life quality (10,11).

Vitiligo is associated with numerous psychological problems, including depression, low self-esteem, anxiety, social anxiety, and sexual problems (11). Stigma is a psychological label referring to a negative attitude toward oneself due to their perceived differences from others. Due to vitiligo's detrimental effects on a person's appearance, it can result in high levels of stigma, leading to psychological stress and negatively impacting patients' quality of life (12).

Studies have shown that most chronic diseases, especially ones that affect the skin, like Acne vulgaris, Alopecia Areata, Psoriasis, and syphilis, experience a significantly high degree of shame stigma due to the importance of skin in daily social interactions (13,14).

Numerous studies have evaluated the relationship between psychological disorders such as depression or anxiety and vitiligo. However, there aren't enough studies about how stigma and related factors impact vitiligo patients' quality of life. In this study, the prevalence of stigma and its associated factors have been examined to investigate its effect on patients' quality of life.

Materials and Methods

This is a cross-sectional study from October 2019 to August 2020 investigating the prevalence and determinants of the stigma experienced by patients with vitiligo. Three hundred twenty-three patients with vitiligo attended Razi Hospital, Tehran, Iran, in 2018-2019 and were enrolled in the study.

The inclusion criteria for the study included patients aged 16 and older with a clinical diagnosis of vitiligo. Initially, the objectives were explained to participants, and if they agreed to participate in the study, demographic, stigma, and DLQI questionnaires were filled out with the assistance of a physician. The collected data included information regarding age, sex, marital status, education, employment status, disease onset time, lesion site, underlying diseases, type of treatment, and suicide history.

Regarding DLQI, which included ten items, each item was assessed on the following scale: very high=3 points, high=2 points, low=1 point, and not relevant=0 points.

The questionnaire is graded on a scale of zero to thirty. It is also graded qualitatively according to the following:

0-1: no effect on the patient's life
2-5: small impact on patient's life
6-10: moderate effects on patient's life
11-20: very large effect on patient's life
21-30: extremely large impact on patient's life

In terms of stigma assessment, Ginsburg and Link (1989) FSQ (Feeling of Stigmatization Questionnaire) questionnaire was used.

The FSQ questionnaire consists of 33 items in six dimensions (anticipation of rejection, feeling of being flawed, sensitivity to opinions of others, guilt and shame, positive attitude, and Secretiveness), each of which item is scored on a 6-point Likert scale. The total scores obtained from the questionnaire are between 198 and 33, which show an inverse relationship with the level of stigma experienced.

To ensure the reliability and validity of the questionnaire, the English questionnaire was translated into Persian by two persons fluent in both English and Persian who are aware of the scientific background of the questionnaire. Then, it was reviewed scientifically by the research team. After correcting a few minor errors, the Persian questionnaires were translated again independently into English by two bilingual individuals. The final questionnaires were compared with the original one. Finally, the Persian questionnaire, which was the most consistent in terms of content and understanding with the main questionnaire, was selected.

To test the validity and reliability of the FSQ, 97 patients with psoriasis who were referred to the follow-up clinic, the phototherapy unit, and patients admitted to Razi Hospital during 2018-2019 were selected and asked to complete the questionnaire. Ten patients were excluded due to loss to follow-up, while another 87 patients were asked to re-complete the questionnaire after ten days. The 10-day period is set to ensure that patients do not recall their previous responses and that their symptoms do not change significantly during the therapy period.

The analysis resulted in Cronbach's score being 0.925 for a set of 33 questions, and according to Cronbach's oligarchy, there was a relatively high degree of internal consistency between the questions. Also, during the analysis, no significant change in the alpha Cronbach coefficient was observed with the removal of each questionnaire item, indicating the appropriateness of the questionnaire's translation. In our study, one of the questionnaire items was removed due to irrelevancy to vitiligo clinical features (that item was about surveying patients' feelings when asked to clean scales that are fallen from the skin). To determine the frequency and percentage, mean, standard deviation, interquartile range, and range of the data were measured, and a 95% confidence interval was defined to express the accuracy of the estimates. Independent t-test, chi-square, and Fisher's exact test were used to test the relationship between different variables in this study. All analyzes were performed with SPSS 24.0 statistical software.

Results

From October 2019 to August 2020, data concerning 323 patients (179 (55.4%) women and 144 (44.6%) men) with a mean age of 36.2 years (SD: 119, range: 17-67) were analyzed. The mean duration of the disease was 9.7±9.3 years (range: 1-55). The most common sites for vitiligo were hands/forearms with 77.4%, legs/feet with 69%, trunk with 55%, and face with 48%. As for the underlying diseases, 45 (13.9%) patients had thyroid disease, and 16 (5%) patients had diabetes mellitus. Table 1 summarizes data regarding demographic and clinical data.

Table 1. Demographic and clinical information, Levels of disturbance in quality of life, and frequency of stigmatization level in patients studied

				Frequency	Percent
Demographic and Clinical data	**Marital status**	**Single**		96	29.7
		Married		227	70.3
	Education level	**Illiterate**		9	2.8
		Primary		56	17.3
		Diploma		130	40.2
		Post diploma		23	7.1
		Bachelor		87	26.9
		Master		18	5.6
	Employment status	**Employed**		177	54.8
		Unemployed		146	45.2
	History of previous treatment	**Topical**	**yes**	177	54.8
			no	146	45.2
		Oral	**yes**	57	17.6
			no	266	82.4
	History of depression	**Male**	**Yes**	12	8.3
			No	132	91.7
		Female	**Yes**	18	10.06
			no	161	89.94
Quality of life	**No effect**			44	13.6
	Small			77	23.8
	Moderate			105	32.5
	Large			87	26.9
	Extremely large			10	3.1
Severity of stigma	**Mild**			119	36.8
	Moderate			161	49.8
	Severe			43	13.3

Based on DLQI, the average quality of life score was 7.8±5.6 (range:0-30) (Table 1). Furthermore, 60% of patients experienced moderate to severe life quality disturbance levels, and 13.6% did not affect them. The analysis also revealed significantly higher life quality disturbance in the female gender (*P*<0.001). The FSQ questionnaire score was divided into three categories: mild, moderate, and severe. Moderate and severe experienced stigma was seen in 49.8% and 13.3% of patients, respectively (Table 1). Besides, there was a strong correlation between the gender of the patients and their sense of stigma, as women were significantly more stigmatized than men (*P*=0.008) (Table 2). Nevertheless, there was no significant correlation between patients' age, marital status, education level, employment status, disease duration, underlying diseases, and the stigma they experienced.

Regarding the relation between the degree of life quality disturbance due to vitiligo and the variables of stigma, a significant inverse correlation was observed between scores (r=-0.715, *P*<0.001), which shows that the quality of life disturbance is directly related to the amount of stigma experienced by patients (Figure 1).

In the stigmatization dimensions' analysis, the anticipation of rejection and guilt and shame were the most common factors with a mean score of 3.2 and 3.75, respectively, and a positive attitude was the least stigmatization factor experienced (mean:4.28±1) (Table 3).

The study also demonstrated that patients with vitiligo lesions on their face, hands, and forearms experienced higher levels of stigma than those with lesions on other parts of their body (*P*.001). On the other hand, it was found that the stigmata level was negatively related to the presence of lesions on the trunk and thighs (*P*=0.03, 0.047). Furthermore, the presence of vitiligo lesions on other sites (including the head, neck, breast, shoulder, arm, genital area, leg, and feet) was not related to the degree of stigma (Table 2).

Concerning the relationship between the type of treatment and the level of stigma experienced, topical or oral treatment was associated with a higher stigma level (*P*=0.003). Concurrently, patients with a history of depression were also significantly more likely to experience stigma (*P*.001) (Table 2).

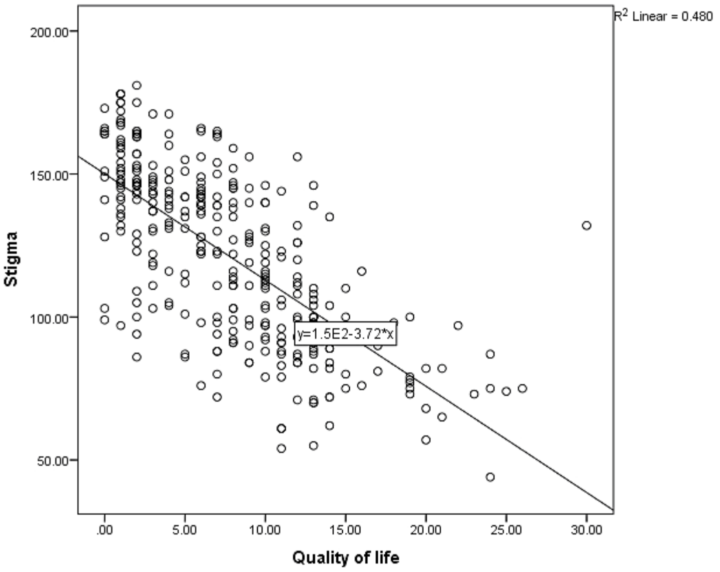

Figure 1. Relationship between dermatology quality of life and stigma level

Table 2. Significant correlations between stigma severity and variables

Variable			Mean	Standard Deviation	*P*
Gender		**Male**	126.04	30.33	0.008
		Female	117.00	29.81	
location	**Face**	**Yes**	106.62	26.69	<0.001
		No	134.32	27.33	
	Forearm and hand	**Yes**	117.66	29.86	<0.001
		No	132.54	29.27	
	Trunk	**Yes**	124.33	29.95	0.03
		No	116.97	30.41	
	Thigh	**Yes**	124.65	31.48	0.047
		No	117.93	29.05	
Previous treatment	**Topical**	**Yes**	116.55	30.55	0.003
		No	126.45	29.26	
	Oral	**Yes**	110.10	28.38	0.003
		No	123.37	30.27	
History of depression		**Yes**	101.73	24.17	<0.001
		No	123.00	30.24	

Table 3. The scores of the six items of stigmatization

Factors	Gender	Mean	Standard Deviation
1. Anticipation of rejection	Female	3.07	1.01
	Male	3.36	1.04
	Total	3.20	1.03
2. Feeling of being flawed	Female	3.83	1.08
	Male	4.12	1.18
	Total	3.96	1.13
3. Sensitivity to the opinions of others	Female	3.92	1.18
	Male	4.04	1.04
	Total	3.97	1.12
4. Guilt and shame	Female	3.60	1.18
	Male	3.93	1.10
	Total	3.75	1.15
5. Positive altitudes	Female	4.24	1.12
	Male	4.32	0.94
	Total	4.28	1.04
6. Secretiveness	Female	3.68	1.11
	Male	4.21	1.21
	Total	3.92	1.18

Discussion

This prospective study revealed that patients with vitiligo suffer from high levels of stigma. The stigma was higher in women and patients with face, hand, and forearm lesions. Furthermore, there was a strong correlation between the level of stigma and disturbance in life quality. This study shows that, in 86.4% of vitiligo patients, quality of life was affected to varying degrees. This suggests the importance of assessing the quality of life in these patients. Other studies have also reported a high incidence of quality of life disorders in patients with vitiligo (15,16). In the meantime, feeling stigmatized is an important factor affecting patients' quality of life with vitiligo (17).

Psychological impacts of skin illnesses, including stigma experience, shame, depression, anxiety, and stress, are seen in various dermatological problems (13,14,18). A relatively high level of embarrassment and stigma was seen in acne vulgaris, psoriasis, alopecia Areata, and syphilis, according to previous surveys (13,14). Therefore, it is crucial to investigate the severity of stigma and its related factors.

In the current study, we have translated the Persian version of the FSQ questionnaire for use in the study and evaluated its structural reliability and validity. This study indicates that 63.2% of patients experienced moderate to severe forms of stigma (moderate=49.8% and severe=13.3%). In accordance with our studies, others have found that these patients' stigma levels exceed 50% (19,20). However, the study of Rajan Pichaimuthu *et al.*, indicates that stigma levels were lower (21).

Analyzing the demographics with the FSQ and DLQI questionnaires, we found that women experienced significantly more stigma than men (P=0.008). This might be because women tend to pay more attention to cosmetic defects (22). In the study conducted by G-Schmid-ott *et al.*, similar to our own, the severity of stigma was reported to be greater in women (22). However, this relationship was not significant in S. Sawant *et al.*, study (20). Furthermore, patients with vitiligo lesions on the face or hands, forearms, or neck have significantly greater stigma than patients with lesions on the other parts of the body (P 0.001). This is because these areas are more visible (22), which is also why patients who had only lesions on the trunk or thighs were less likely to feel stigmatized (19,22). Other studies also support this result (19,22).

The severity of stigma was also greater in patients with a history of either oral or topical treatments. This result could be due to the higher severity of the disease in patients with oral treatment histories and possible difficulties related to treatment with topical agents.

We observed a remarkable correlation between the scores on the questionnaires on quality of life and the level of stigma they experienced, indicating that stigma can profoundly affect the quality of life.

Last but certainly not least, patients with depression had a greater sense of stigma, showing the importance of psychological issues in vitiligo patients again. This relationship was also investigated in the study of Sawant *et al.*, (20) and found to be significant.

There are very few studies focusing on stigma relating to dermatological conditions and specifically vitiligo. The skin is the outermost layer of the human body and is the most visible part. It is therefore not surprising that, at first glance, many are judged by their physical appearance, which one of the most prominent characteristics is their skin. In this study, in addition to evaluating the level and related factors of stigma in vitiligo, which has been but little studied, we also explored the effect of stigma on quality of life in patients with vitiligo. Another strength of the current study is the relatively large study population. In addition, there are some limitations related to the study, such as collecting patients from the skin hospital lacking a control group and not using the vitiligo area severity index (VASI) for evaluating the severity of vitiligo.

This study's findings emphasize the importance of considering stigma and its impact on patients' quality of life with vitiligo. Reducing stigma by considering psychological issues in these patients is the most important way to increase their quality of life. It is hoped that more studies will be conducted to emphasize this issue and its importance in the treatment of patients with vitiligo.

The results indicate that stigma and decreased quality of life are common in patients with vitiligo. The degree of stigma is directly related to the degree of quality of life disturbance. Other factors influencing the severity of stigma include the female gender, the location of the lesions (forearm, hand), topical or oral treatments, and the history of depression.

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