Is a Poor Dermatology Life Quality Index Score a Sign of Stigmatization in Patients with Vitiligo?

Vitiligolu Hastalarda Dermatoloji Yaşam Kalite İndeksindeki Bozulma Stigmatizasyon Göstergesi mi?

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Geliş Tarihi/*Received:* 16.02.2014
Kabul Tarihi/*Accepted:* 30.04.2014

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ABSTRACT Objective: Vitiligo causes milky white patches on the skin and leads to significant impairment in quality of life. Although many chronic skin diseases potentially lead to stigmatization, there are only a limited number of studies investigating how stigmatized people with vitiligo feel. The purpose of this study was to evaluate the feeling of stigmatization vitiligo creates in people and investigate the association between Dermatology Life Quality Index (DLQI) scores, demographical and clinical data. **Material and Methods:** A total of 38 patients with vitiligo who were seen in the outpatient dermatology clinic of our hospital during January and May 2013 were included in this cross-sectional study. Demographic data, skin type, duration of disease, involved regions of the body, number of plaques and previous treatments were noted for each patient. Later on, DLQI and Feeling of Stigmatization Questionnaire were applied to the patients. **Results:** The total mean stigmatization score was 86.85±28.14 (14-135) and the mean DLQI score was 6.02±2.55 (2-14) among a total of 34 patients with vitiligo (19 females, 15 males) included in this study. Multivariate correlation analysis showed a significant correlation between these two values ($p<0.001$). **Conclusion:** Vitiligo is related to impaired quality of life and the feeling of stigmatization has a prominent role in the poor quality of life in these patients. Awareness should be raised among general population about vitiligo as well as other skin diseases.

Key Words: Vitiligo; stereotyping; quality of life

ÖZET Amaç: Vitiligo deride süt beyaz lekelere yol açar ve yaşam kalitesinde belirgin bozulmaya sebep olur. Pek çok kronik deri hastalığı stigmatizasyona (damgalanma) yol açsa da vitiligolu hastaların ne kadar damgalanmış hissettirdiğini gösteren sınırlı sayıda literatür çalışması vardır. Bu çalışmanın amacı vitiligonun hastalarda yolaçtığı damgalanma hissini değerlendirmek ve dermatoloji yaşam kalite indeksi (DYKİ) skorları, demografik ve klinik veriler ile ilişkisini araştırmaktır. **Gereç ve Yöntemler:** Bu kesitsel çalışmaya 2013 Ocak ve Mayıs ayları arasında hastanemiz genel dermatoloji polikliniğine başvuran 38 vitiligolu hasta dâhil edildi. Her hasta için demografik verileri, deri tipi, hastalık süresi, tutulan bölgeler, tutulan plak sayısı, önceden yapılan tedaviler kaydedildi. Daha sonra hastalara stigmatizasyon hissetme anketi ve DYKİ anketi uygulandı. **Bulgular:** Çalışmaya katılan toplam 34 (19 kadın, 15 erkek) vitiligo hastasında ölçülen ortalama toplam stigmatizasyon skoru 86,85±28,14 (14-135), ortalama DYKİ skoru ise 6,02±2,55 (2-14) idi. Multivaryans korelasyon analizlerinde bu iki değer birbiriyle ilişkili bulundu ($p<0,001$). **Sonuç:** Vitiligo yaşam kalitesini etkiler ve çalışmamıza göre düşük yaşam kalitesinde hastaların hissettiği damgalanma duygusunun belirgin rolü vardır. Toplumda vitiligo ve diğer deri hastalıkları ile ilgili farkındalık düzeyi arttırılmalıdır.

Anahtar Kelimeler: Vitiligo; stereotip; yaşam kalitesi

Turkiye Klinikleri J Dermatol 2014;24(2):45-50

Stigmatization is the state of having degrading signs which disrupts normal interpersonal relations and causes social discrimination and alienation. It may be caused by a visible physical defect or a negative trait or condition or a memory of the past. Actually, stigmatization is the state of being marginalised which dates back to old times and the oldest example of stigmatization that is known is *lepra*, a well-known skin disease.[1]

Skin plays an important role in interpersonal relations. Especially those skin diseases which have obvious effects on physical appearance may cause psychological and social hardships as well as physical difficulties for patients. When they create visible changes on the skin, skin diseases may arouse fear, disgust, hatred and intolerance among people.[2] Therefore, stigma is one of the most important psychological problems created by skin diseases. In a literature search, many studies can be found which investigate stigmatization especially caused by psoriasis.[2-5] There are many chronic skin diseases that may lead to stigmatization; but there are only a limited number of studies investigating feeling of stigmatization in these patients with chronic skin diseases.[6,7] Indeed, staring at the skin of patients with a skin disease by others, is the primary discomfort felt.

Vitiligo is an acquired idiopathic progressive skin disease which results in white patches in the skin due to loss of normal pigmentation of the parts of the skin or total depigmentation of the skin. Frequency of vitiligo among people may range from 0.5 to 1% and it significantly reduces the quality of life.[8] It is believed that reduction in the quality of life is directly associated with the feelings of stigmatization caused by vitiligo.[9] The purpose of this study was to evaluate the feelings of stigmatization created by vitiligo and investigate the association between life quality index scores and demographic and clinical data.

MATERIAL AND METHODS

PATIENT SELECTION

This cross sectional study was conducted among 38 patients with vitiligo who were consequetively seen in the outpatient dermatology clinic of our hospital during January and May 2013. The study was approved by the local ethics committee (2013/14) and conducted according to the Declaration of Helsinki guidelines. Demographic data such as age, gender, educational status, economic status, marital status, place of live; and clinical data including skin type, duration of disease, involved body areas, number of plaques and previous treatments were noted for each patient who accepted to participate in the study. Patients with additional visible skin diseases or scars as well as patients carrying diagnoses of various psychiatric disorders and those who were under the age of 18 were excluded from this study.

STIGMATIZATION QUESTIONNAIRE

Patients were asked to complete a stigmatization questionnaire consisting of 33 items and developed by Ginsburg and Bink.[4] Each item scored on a 6 point scale as: 0=strongly disagree, 1=disagree, 2=partially disagree, 3=partially agree, 4=agree and 5=strongly agree. Reverse scoring was applied for items 16, 20, 22-25, 27 and 28. Total scores ranged from 0 to 165 and the feeling of stigmatization increased as the patient scored higher. In this questionnaire, stigmatization was evaluated by six dimensions as follows: anticipation of rejection (item 8), feelings of being flawed (item 6), sensitivity to the opinions of others (item 5), feelings of guilt and shame (item 5), secretiveness (item 5), positive attitudes (item 4).

EVALUATION OF THE QUALITY OF LIFE

Patients also completed, considering their conditions of the last week prior to admission, the Dermatology Life Quality Index (DLQI) consisting of 10 questions and developed by Finlay and Khan.[10] Validity and reliability of the Turkish version of this questionnaire was shown by Ozturkcan et al.[11]

STATISTICAL ANALYSIS

All data were analysed by means of SPSS version 18.0. Characteristics of the population were identified by means of descriptive methods. As data did not show a normal distribution, non-parametric tests were used. Differences in scores between female patients and male patients were compared by means of Mann Whitney-U test. Correlation between total stigmatization and DLQI scores and dermatological and clinical data was evaluated by means of Kendall's tau correlation analysis. Limit of statistical significance was set at p<0.05.

RESULTS

SOCIO-DEMOGRAPHIC AND CLINICAL DATA

Four patients were excluded from the study as they did not complete the questionnaires. The mean age of a total of 34 patients with vitiligo (19 females and 15 males) who completed the questionnaires was 32.68±12.00 (range 18-60) years and the mean duration of disease was 6.65±6.61 years (range 1-300 months). Demographic and clinical data of the vitiligo patients were shown (Table 1). In 29 patients, lesions were visible from a face-to-face conversation distance. There was no significant difference between female patients and male patients in duration of disease, involved regions and severity of disease (p=0.651, p=0.615 and p=0.083, respectively).

EVALUATION OF STIGMATIZATION

The total mean stigmatization score was 86.85±28.14 (14-135) among patients with vitiligo; 90.74±20.41 among female patients; and 81.93±35.85 among male patients (p=0.493). The mean stigmatization sub-scores with gender variations are demonstrated (Table 2). No significant differences were found between sexes in stigmatization scores.

EVALUATION OF THE DLQI

The mean DLQI score was 6.02±2.55 (ranging from 2 to 14) among patients with vitiligo; 6.11±2.69 among female patients; and 5.93±2.46 among male patients. No significant differences were found between sexes in DLQI scores (p=0.902).

EVALUATION OF FACTORS IMPACTING ON STIGMATIZATION AND DLQI SCORES

Multivariate correlation analysis suggested a correlation between total stigmatization score and DLQI score (p=0.001, r=0.548). In addition, no significant association was found between total stigmatization and DQLI scores and age of the patient, age of onset of disease, duration of disease,

TABLE 1: Demographic and clinical features of patients with vitiligo.

Variables	n (%)
Age (year, mean±SD)	32.67±12.00
Age of onset of disease (year, mean±SD)	26.02±14.10
Gender (female, %)	19 (55.9)
Marital status (married, %)	22 (64.7)
Economic status (good, %)	26 (76.5)
Educational status (university graduates, %)	9 (26.5)
Domicile (city centre, %)	26 (76.5)
Use of disguise (yes, %)	12 (35.3)
Involved regions	
Face	22 (64.7)
Hands	20 (58.8)
Trunk	28 (82.4)
Comorbidity (yes, %)	12 (35.3)
Family history (positive, %)	13 (38.2)
Previous treatments (yes, %)	25 (73.5)
Current treatments (yes, %)	22(64.7)

TABLE 2: Results of stigmatization questionnaire and DLQI in both female and male patients with vitiligo.

	All patients mean score±SD	min/max	Female patients mean score±SD	Male patients mean score±SD	p value
Total stigmatization score	86.85±28.14	14/135	90.73±20.41	81.93±35.85	0.477
Anticipation of rejection	17.21±8.20	0/35	18.79±5.22	15.20±10.75	0.175
Feelings of being flawed	16.09±7.70	1/28	17.68±6.46	14.07±8.84	0.198
Sensitivity to the opinions of others	13.38±5.30	0/21	13.42±4.83	13.33±6.02	0.848
Feelings of guilt and shame	11.91±3.87	2/18	11.95±3.55	11.87±4.37	0.944
Secretiveness	14.88±4.25	7/22	15.10±4.37	14.60±4.22	0.715
Positive attitudes	13.38±5.41	0/20	13.79 ±4.45	12.87±6.55	0.931
DLQI	6.02±2.55	2/14	6.11± 2.69	5.93±2.46	0.902

Mann Whitney-U test.

number of plaques, severity of disease and involved body parts.

USE OF CAMOUFLAGE TO CONCEAL THE DISEASE

Twelve patients stated that they were routinely using various methods of camouflage to hide their lesions. The most frequent method was cosmetic camouflage (6) among patients with vitiligo, followed by clothes (4) and body movements (2).

DISCUSSION

Psychosocial effects of vitiligo were first investigated by Porter et al. in 1970s.[12] Various studies conducted since then have reported an increase in the prevalence of depression, anxiety, stigmatization, lack of self-confidence, and impairment in relations with the opposite sex among patients with vitiligo.[13-18] Dermatology-specific tests are frequently used in evaluation of effects of a group of skin diseases including vitiligo on the quality of life. One of such tests is DLQI which has been used by a majority of studies since it was developed by Finlay and Khan.

Factors impacting on DLQI scores can mainly be divided into two as objective factors and subjective factors.[19] Objective factors can be listed as follows: personal factors such as age and sex; disease-related features such as duration of disease, involved regions of the body and clinical severity of disease; laboratory features; and socioeconomic status. Subjective factors, on the other hand, are how one thinks of oneself and of own disease; mental state; social status; and relations with other people. These factors were investigated in few studies assessing the DLQI scores in patients with vitiligo. Kent and Al-Abadie were the first researchers to use the DLQI in patients with vitiligo in 1996.[20] In their study, which was conducted in the UK, they found that the mean DLQI score was 4.82 among a total of 614 patients with vitiligo. In addition, the DLQI score was not associated with age and sex but was strongly associated with racial differences as well as negative symptoms caused by depression, anxiety, nervousness, anxiousness, hopelessness and loneliness, lack of self-confidence and particularly the feelings of stigmatization. Since then, many studies investigated the DLQI scores in vitiligo patients with scores ranging from 1 to 10.67.[21-24] The higher DLQI scores were observed in studies from India and Northern Tanzania, which may be attributed to the darker skin and the obvious contrast created by vitiligo lesions.[21,22] Besides most of the studies found an association with the body surface area and number of body regions affected by the disease.[23,24] In agreement with the literature, the mean DLQI score was found to be 6.02 in the present study. However, analyses suggested no association between this score and demographic and clinical data of the patients. On the other hand, a strong association was found between total stigmatization score and DLQI score.

As vitiligo is a chronic recurrent disease which creates visible lesions and obvious cosmetic disorders, it may frequently cause stigma and stigmatization. Actually, stigma is a triggering factor on its own for impairments in mental health.[25] In their study, Kent and Al-Abadi showed that experience of stigmatization caused a variance of 39% in the quality of life. A similar study divided patients with vitiligo into two as those with visible lesions and those without and found a significantly higher total stigmatization score among patients with visible lesions.[16] In another study, the authors investigated the feelings of stigmatization among British female patients who were immigrants from South Asia and concluded that ethnic and cultural differences were significantly influential on the feelings of stigmatization.[26] In a recent study among paediatric patients with vitiligo, the authors assessed the Children's Dermatology Life Quality Index (CDLQI) scores and feelings of disease-related isolation, exclusion and stigmatization among the patients and compared them to a control group. They concluded that higher scores were associated with stigmatization, use of camouflage, involvement of the face, negative family history and restrictions in social life.[27] In the present study, a significant association was found between total stigmatization score and DLQI score. On the other hand, total stigmatization score was found to have no associations with demographic and clinical data of the patients.

Vitiligo is usually a demoralising disease with chronic variable course and there is not any specific treatment which produces the same effects on each patient. When patients with vitiligo were asked about their disease, many of them thought that their disease was incurable.[28] Furthermore, many physicians may overlook the psychosocial aspects of this disease which they may think is merely a cosmetic problem.[8] Actually, severity of the clinical involvement of the disease as well as psychological and social problems it creates should be taken into consideration in planning the treatment. In agreement with the literature, the present study revealed that the disease created significant psychosocial effects, irrespective of the clinical severity. In this respect, informing the patient and his/her family about the disease as well as treatment modalities and raising awareness among the general population about the disease can be mentioned among the most important methods that can be used to alleviate the feelings of stigmatization.

It has been reported that many skin diseases are preceded by a stressful event or psychological trauma.[29] Actually, a majority of the patients tend to associate their skin disease with a preceding event. Full light is yet to be shed on the aetipathogenesis of vitiligo. Theories explaining the loss of melanocytes are based on autoimmunity, autocytotoxicity, oxidative stress and neurohumoral mechanisms.[30] There are retrospective epidemiologic studies indicating the role of psychological stress in vitiligo.[31] However, it is yet to be known how hormones released at stressful moments become influential on the pathogenesis of the disease. Vitiligo-related stigmatization is a source of stress and may affect the course of the disease. On the other hand, there is no study in the literature investigating the clinical healing process of patients who have been given psychosocial support.

The major limitation of this study is relatively small sample size. This prestudy aids in understanding role of feeling of stigmatization in quality of life among patients with vitiligo. A more robust approach to this question would be to undertake a qualitative study exploring feelings of stigmatization in vitiligo, what factors affect it and how large a part it plays in lowering quality of life. Furthermore the Turkish version of the stigmatization questionnaire was not validated.

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