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Evaluation of Internalized Stigma and Quality of Life of Patients with Psoriasis

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Abstract

Background: Internalized stigma is defined as individuals' acceptance of negative stereotypes created by society and then their alienation from society. Psoriasis is a dermatological disease that affects the quality of life. The study evaluated the internalized stigma and quality of life of patients diagnosed with psoriasis.

Methods: This cross sectional study enrolled 222 patients. Data were collected using the internalized stigma scale and the dermatology life quality index questionnaires. Data were analyzed using the Cronbach's alpha.

Results: The internalized stigma score of the patients was 78.41 ± 23.14, and the quality of life score was 12.30 ± 5.67. Stigmatization and quality of life were affected by patients' physical, psychological, and social lives ($p < 0.05$).

Conclusions: Patients' internalized stigma level was high, their quality of life was low, and their quality of life decreased as the internalized stigma level increased. Furthermore, the internalized stigma level of the patients who suffered more from psoriasis was higher, but their quality of life was lower than those who suffered less.

Keywords: patient, psoriasis, quality of life, stigma

INTRODUCTION

Psoriasis is a dermatological disease where stigmatization is common.[1,2] The World Health Organization (WHO) prepared a global report to reduce the disease burden in patients with psoriasis, enable them to combat stigma and exclusion, and increase their healthcare and social participation. In 2014, the WHO declared psoriasis a noncommunicable disease to increase awareness of its stigma.[3] Internalized stigma is the feeling of stigma experienced by the individual despite not being stigmatized by the society.[4] Internalized stigma is defined as individuals' acceptance of negative stereotypes created by society and subsequent withdrawal from society, with feelings such as worthlessness and shame.[1,5,6] Psoriasis, which is a visible disease, leads to feeling shy and embarrassed, thinking one has a defect, and having a negative body image, fear, loneliness, stress, and loss of self-confidence.[7,8] Patients experience hopelessness about the symptoms and treatment. Psoriasis is a stigmatizing disease and causes higher levels of stigmatization than other dermatological diseases.[9]

Researchers have stated that psoriatic lesions may be an important determinant of psychosocial functioning and that the lesions may cause stigma and decrease the quality of life of patients.[2] Even a small plaque lesion in psoriasis may be enough for patients to feel stigmatized. Researchers have also explained that the quality of life of patients with psoriasis is as important as those with other chronic diseases because they experience high levels of stigma. Moreover, a study reported that quality of life and stigma interact with each other in patients with psoriasis; thus, they should be considered together.[1]

Lesions, itching, and flaking seen in patients with psoriasis decrease their quality of life.[10] Although psoriasis is benign, it is a lifelong skin disease. Experience of relapses decreases the quality of life of patients with psoriasis.[11] Psoriasis affects the physiological and psychological life of the patients, causing a decrease in social functionality and deterioration of interpersonal relationships.[12,13]

No studies have discussed the internalized stigma and quality of life of patients with psoriasis living in a city located in the east of Turkey. This study investigated the internalized stigma, quality of life, and affecting factors in patients with psoriasis.

METHODS

The research was conducted in accordance with the principles of the Declaration of Helsinki. The patients were informed about the study, and their consent was obtained. The study was approved by the ethics committees of the Ataturk University Faculty of Health Sciences (No. 2018-2/6) and of the hospital where the study was conducted (No. 42190979-000-E.1800130824).

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This descriptive and cross-sectional study was enrolled patients with psoriasis who were admitted to Ataturk University Research and Application Hospital Dermatology Outpatient Clinic between March 2018 and February 2019. Between these dates, 240 patients were interviewed. Of these patients, 18 were excluded because they did not agree to participate in the study; finally, the study enrolled 222 patients. Psoriasis patients aged ≥18 years, those who had adequate communication, and those who agreed to participate were included in the study. In the power analysis, the statistical power of the research was 0.99 at 95% confidence interval and 0.05 significance level, showing that the sample size was sufficient.[14] Study data were collected using the internalized stigma scale and dermatology life quality index questionnaires.

The researcher-prepared questionnaire was in line with the literature.[12,15] Before starting the study, a pilot study was conducted with 10 patients. The final questionnaire contained 21 questions, including sociodemographic characteristics of patients with psoriasis such as age, sex, education, and employment status and disease-related variables such as the duration of the illness and effect of the disease on psychological status, family, work, and social life.

The internalized stigma scale was developed by Ritsher *et al*. to measure the subjective stigma experience of individuals.[16] The scale can be used for psoriasis and mental illness. The Turkish validity and reliability study of the scale for patients with psoriasis was performed by Alpsoy *et al*.[17] The scale consists of 29 questions. Responses to the items in the internalized stigma scale are given according to a 4-point Likert-type scale, including "strongly disagree" (1 point), "disagree" (2 points), "strongly agree" (3 points), and "strongly disagree" (4 points). The total scale score ranges from 29 to 116. High scale scores indicate that more severe internalized stigma. The Cronbach's alpha value in the reliability study of the scale conducted with patients with psoriasis was 0.89.[17] In the present study, the Cronbach's alpha value of the scale was 0.98.

The dermatology life quality index, a self-administered questionnaire widely used in dermatological diseases, consists of 10 questions addressing the issues most complained about related to the quality of life over the last week. The questions cover the following topics: symptoms and emotions (questions 1 and 2), daily activities (questions 3 and 4), hobbies (questions 5 and 6), work and school (question 7), personal relationships (questions 8 and 9), and treatment (question 10). In the scale, nine questions are answered according to a Likert-type scale (0, not at all; 1, a little; 2, a lot; and 3, very much). Question 7 is answered "yes" or "no." In question 7, if the answer is "yes," it is scored as 3; however, if the answer is "no," it is scored as 0. The total scale score is the sum of the scores of each question. The maximum and minimum scores of the scale are 30 and 0, respectively. As the score increases, the quality of life decreases. Öztürkcan *et al*. performed the Turkish validity and reliability study of the scale, and Cronbach's alpha was 0.87 in the validity and reliability study.[18] In the present study, the Cronbach's alpha value of the scale was 0.87.

Data were analyzed using SPSS Statistics for Windows, version 17 (SPSS Inc., Chicago, IL, USA). Numbers, percentages, mean, and standard deviation were used in the data analysis. Skewness and kurtosis were used to examine whether the data were normally distributed. Independent samples t-test, one-way analysis of variance, least significant difference, Pearson's and Spearman's correlation test were used for data analysis.

RESULTS

Table 1 shows age, disease period, life quality, and internalized stigma of the patients. The mean internalized stigmatization score and quality of life score of the patients were 78.41 ± 23.14 and 12.30 ± 5.67, respectively (Table 1). The majority of the participants were women (51.8%), married (60.4%), higher education graduates (54.1%), unemployed (55.4%), and living in the city center (55%). Of the patients, 28.3% visited the hospital for treatment and 52.3% for their symptoms, 40.5% did not receive treatment regularly, 20.7% had another disease, 15.8% had psoriatic arthritis, and 35.6% had a family member with psoriasis. Of the patients, 46.8% were smokers, and patients reported that their psychological (80.2%), physical (91.9%), and sexual health (14.4%), family (23.4%), work (17.6%), and social life (69.8%) were affected (Table 2).

The internalized stigma and quality of life scores were significantly higher in patients who visited the hospital for treatment and symptoms, did not receive treatment regularly, had other illnesses and psoriatic arthritis, had a family member with psoriasis, were smokers, and reported that psychological, physical and sexual health, family, work, and social life were affected ($p < 0.05$) (Table 3).

A significant difference was found between the reasons for the patients visit to the hospital for treatment and the internalized stigma and quality of life scores ($p < 0.05$). Further analysis showed that the mean internalized stigma and quality of life scores for those who visited the hospital for treatment and symptoms were higher than for those visiting for follow-up (Table 3).

A significant moderate positive relationship was found between the internalized stigma and quality of life scores ($p < 0.05$) (Table 4). The mean patient age and disease duration were 36.95 ± 12.42 and 11.77 ± 10.86, respectively. A significant positive correlation was found between age and disease duration and internalized stigma and mean quality of life scores ($p < 0.05$).

The internalized stigma scores of those who were female, married, unemployed, and lived in villages were higher

than those of their counterparts, but the difference was not significant. As the education level of the patients decreased, the mean internalized stigma score increased, but the difference was not significant. No significant association was found between sex, place of residence, and marital, educational, and employment statuses with the mean quality of life scores ($p > 0.05$).

TABLE 1. Age, disease period, life quality, and internalized stigma of the patients

Variables	Mean ± SD
Age, years (min–max, 18–68)	36.95 ± 12.42
Disease period, years (min–max, 1–50)	11.77 ± 10.86
Life quality (min–max, 0–26)	12.30 ± 5.67
Internalized stigma (min–max, 29–109)	78.41 ± 23.14

TABLE 2. Patients' characteristics (N = 222)

Variables	Frequency (N)	Percentage (%)
Sex		
Female	115	51.8
Male	107	48.2
Marital status		
Married	134	60.4
Single	88	39.6
Educational status		
Literate	10	4.5
Primary school	20	9.0
Secondary school	24	10.8
High school	120	54.1
University	48	21.6
Employment status		
Employed	99	44.6
Unemployed	123	55.4
Place of residence		
Village	21	9.4
District	79	35.6
City	122	55
Reason for visiting hospital		
Symptoms	116	52.3
Follow-up	43	19.4
Treatment	63	28.3
Receiving regular treatment		
Yes	132	59.5
No	90	40.5
Psoriatic arthritis		
Yes	35	15.8
No	187	84.2
Smoking		
No	118	53.2
Yes	104	46.8
Another disease		
No	176	79.3
Yes	46	20.7
Family member with psoriasis		
Yes	79	35.6
No	143	64.4
Psychological health		
Affected	178	80.2
Not affected	44	19.8
Family life		
Affected	52	23.4
Not affected	170	76.6
Business life		
Affected	39	17.6
Not affected	183	82.4
Social life		
Affected	155	69.8
Not affected	18	8.1
Physical health		
Affected	204	91.9
Not affected	18	8.1
Sexual health		
Affected	32	14.4
Not affected	190	85.6

TABLE 3. Comparison of patients' characteristics, internalized stigma, and life quality scores (N = 222)

Variables	Internalized stigma Mean ± SD	*p*	Life quality Mean ± SD	*p*
Sex				
Female	80.23 ± 22.89	0.223[a]	12.20 ± 5.44	0.575[a]
Male	76.44 ± 23.35		12.52 ± 5.91	
Marital status				
Married	78.69 ± 22.81	0.819[a]	12.48 ± 5.61	0.569[a]
Single	77.97 ± 23.76		12.03 ± 5.76	
Educational status				
Literate	86.70 ± 22.72		15.00 ± 7.06	
Primary school	83.65 ± 19.30	0.609[b]	13.60 ± 5.73	0.434[b]
Secondary School	78.25 ± 22.70		12.25 ± 6.10	
High school	77.51 ± 23.48		11.99 ± 5.24	
University	76.81 ± 24.28		12.00 ± 6.14	
Employment status				
Employed	77.64 ± 23.57	0.658[a]	12.09 ± 5.49	0.620[a]
Unemployed	79.02 ± 22.87		12.74 ± 5.82	

TABLE 3. Continued

Variables	Internalized stigma Mean ± SD	*p*	Life quality Mean ± SD	*p*
Place of residence				
Village	82.10 ± 23.05	0.473[b]	13.52 ± 5.72	0.566[b]
District	79.96 ± 22.21		12.30 ± 5.24	
City	76.76 ± 23.78		12.09 ± 5.93	
Reason for visiting hospital				
Symptoms	81.72 ± 21.80	**<0.001**[b]	12.88 ± 5.50	**<0.001**[b]
Follow-up	64.51 ± 24.06		8.51 ± 4.65	
Treatment	81.79 ± 21.65		13.83 ± 5.53	
Receiving regular treatment				
Yes	75.17 ± 24.29	**0.009**[a]	11.65 ± 5.75	**0.038**[a]
No	83.14 ± 20.57		13.26 ± 5.43	
Psoriatic arthritis				
Yes	87.49 ± 21.29	**0.009**[a]	15.63 ± 5.45	**<0.001**[a]
No	76.71 ± 23.13		11.68 ± 5.50	
Smoking				
No	74.09 ± 23.55	**0.003**[a]	11.31 ± 5.69	**0.005**[a]
Yes	83.30 ± 21.76		13.42 ± 5.45	
Another disease				
No	75.22 ± 24.06	**<0.001**[a]	11.55 ± 5.60	**<0.001**[a]
Yes	90.61 ± 13.70		15.17 ± 4.98	
Family member with psoriasis				
Yes	82.67 ± 20.24	**0.041**[a]	13.37 ± 4.68	**0.037**[a]
No	76.05 ± 24.35		11.71 ± 6.08	
Psychological health				
Affected	85.79 ± 18.63	**<0.001**[a]	13.82 ± 4.98	**<0.001**[a]
Not affected	48.55 ± 13.36		6.16 ± 3.85	
Family life				
Affected	94.94 ± 6.33	**<0.001**[a]	17.81 ± 3.93	**<0.001**[a]
Not affected	73.35 ± 24.05		10.62 ± 5.01	
Business life				
Affected	93.36 ± 9.78	**<0.001**[a]	19.05 ± 4.21	**<0.001**[a]
Not affected	75.22 ± 23.92		10.86 ± 4.84	
Social life				
Affected	85.39 ± 14.53	**<0.001**[a]	14.67 ± 4.54	**<0.001**[a]
Not affected	52.99 ± 19.01		5.44 ± 5.04	
Physical health				
Affected	81.06 ± 21.48	**<0.001**[a]	12.91 ± 5.32	**<0.001**[a]
Not affected	48.33 ± 20.27		5.44 ± 5.04	
Sexual health				
Affected	91.66 ± 13.66	**<0.001**[a]	16.78±4.67	**<0.001**[a]
Not affected	76.17 ± 23.68		11.55±5.47	

Bold values: Results are significant if $p < 0.05$.
[a]Independent sample t-test; [b]One-way analysis of variance (ANOVA).

TABLE 4. Correlation of patients' characteristics, internalized stigma, and life quality scores

Variables	r	*p*	r	*p*
Age, years (min–max, 18–68)	0.181	**0.007**[a]	0.155	**0.021**[a]
Disease Period, years (min–max, 1–50)	0.167	**0.013**[b]	0.137	**0.041**[b]
Life quality (min–max, 0–26)	0.745	**<0.001**[a]		
Internalized stigma (min–max, 29–109)			0.745	**<0.001**[a]

Bold values: Results are significant if $p < 0.05$.
[a]Pearson's correlation analysis; [b]Spearman's correlation analysis.

DISCUSSION

In this study, patients with psoriasis were to have high levels of internalized stigmatization and low quality of life. In addition, as the internalized stigma increased, the quality of life decreased. Internalized stigmatization is the feeling of stigmatization experienced by an individual, despite not being stigmatized by society.[4] Internalized

stigma is defined as individuals' acceptance of negative stereotypes created by society and subsequent withdrawal from society, with feelings such as worthlessness and shame.[1,5,6,19] Internalized stigmatization causes a decrease in self-esteem and life satisfaction, an increase in depression and tendency to commit suicide, and difficulty in coping with the disease.[15]

This study determined that patients with psoriasis have high levels of internalized stigma and low quality of life. In addition, as the internalized stigma increased, the quality of life decreased. Studies conducted with patients with psoriasis in various regions of Turkey, except the present study, have high levels of internalized stigma but a low quality of life. Similarly, the quality of life decreased as the internalized stigma increased.[15,17] Intense emotional and psychosocial effects in patients with psoriasis cause stigmatization.[12] Patients with psoriasis who have lesions in visible areas such as the face, nails, and scalp experience high levels of stigma.[17] Patients with psoriasis have higher levels of stigma than patients with acne vulgaris, atopic dermatitis, sun-damaged skin, eczema, or fungal and viral skin infections. The same study also found a relationship between the stigma subscale of the internalized stigma and poor quality of life.[9] The quality of life is low in patients with psoriasis who hide their skin symptoms and retreat from social environments and people.[2,5,20] Psoriasis causes a decrease in the quality of life because of its physical, psychological, and social effects.[2] In line with these results, healthcare professionals should provide necessary training and support for patients with psoriasis to reduce internalized stigma levels and improve their quality of life.

The physical health of a majority of the patients was affected, and their internalized stigma level was high, and their quality of life was low. In this study, 15.8% of the patients had psoriatic arthritis and had similarly high internalized stigma levels and low quality of life. The physical health of patients who have pain, movement limitation, skin involvement, and psoriatic arthritis was negatively affected, and their quality of life was low.[10] A study of patients with psoriasis found that 2.9% had psoriatic arthritis and those with psoriatic arthritis had higher levels of internalized stigma.[15] Another study comparing the effects of skin and joint symptoms in psoriasis found that the feelings of depression, shame, and guilt and the perception that others thought that the disease was contagious were significantly higher in those with skin symptoms.[21,22] Health professionals can contribute to improving the quality of life of patients by reducing the physiological and psychological effects of psoriasis.[23]

In this study, the psychological state of the majority of the patients was affected, and their internalized stigma levels were high, and their quality of life was low. However, others report fewer psychological effects. A study reported that 33% of their patients had depressive symptoms and experienced guilt, rejection, and stigma[4], whereas another reported that 58% of their patients with psoriasis felt ashamed of their appearance and 24% experienced depression.[24] In another study, 58.1% of the patients with psoriasis had depression and higher internalized stigma levels than those who suffered from depression. Stigma leads to a feeling of humiliation, defective thinking, having a negative body image, and low self-esteem.[7] Patients with psoriasis whose psychological status is affected had low quality of life.[25] Skin diseases affecting appearance also influence interpersonal relationships.[26] A study suggested that health professionals should provide the necessary training and psychological and social support for patients with psoriasis.[27]

Skin diseases affect social life and induced patients to feel separate from society.[9] In this study, the social life of the majority of the patients was affected, their internalized stigma level was high, and their quality of life was low. Patients with psoriasis whose social life is affected, hide their lesions, and avoid doing activities where their lesions would appear have higher levels of stigma.[28] A study conducted with Polish patients with psoriasis reported that the disease limited their social life and induced patients to feel a higher level of internalized stigma.[5] Psoriasis limits relationships in the family and among friends, group activities, going to public places, and participating in social activities. Patients with psoriasis who limit their social activities in public areas such as swimming, sunbathing, and going to the beach also have a low quality of life.[29] Patients with psoriasis feel hopelessness and social withdrawal, which negatively affects their quality of life.[30]

In this study, 23.4% of patients' family life and 14.4% of patients' sexual life were affected, and these patients had high levels of internalized stigma and low quality of life. Moreover, the level of internalized stigma was high in married and female participants, but the difference was not significant. A study reported that married patients with psoriasis experienced higher levels of internalized stigma but sex did not affect internalized stigma.[17] Stigma, negative self-esteem, depression, ideas of suicide, anxiety, and sexual dysfunction negatively affect the family and friendship relations of patients with psoriasis.[22,29] Of the patients with psoriasis, 63% had at least one genital involvement in their lifetime, and these patients' psychological condition deteriorated and their quality of life decreased.[31]

In the present study, 17.6% of the patients' business life was affected, and their internalized stigma level was high, and their quality of life was low, but this difference was not significant. Psoriasis negatively affects the ability to work and decreases productivity and quality of life.[5] A study reported that 12% of their patients with psoriasis

were unemployed, and 92% of them could not work because of psoriasis symptoms and psoriatic arthritis.[9] In another study, 60% of the patients with psoriasis quit their jobs because of the illness, requested excessive sick leave from their workplaces, and had low quality of life.[25]

In the present study, 35.6% of the patients had a family member with psoriasis, and these people experienced higher levels of stigma and lower quality of life. Another study found that 32.8% of the participants had a family member with psoriasis and their internalized stigma levels were higher than those without an affected family member.[15] A study of Polish patients with psoriasis determined that those who had a family member with psoriasis understood psoriasis better and received more support from their family members; thus, they coped with the disease better.[5]

In the present study, 20.7% of the patients had another disease. The internalized stigma level of these patients was high, and their quality of life was low. Mental illnesses such as depression and anxiety in patients with psoriasis cause higher levels of stigmatization.[7] Comorbidities such as Crohn's disease, cardiovascular, metabolic, and chronic intestinal diseases, and psychological disorders in patients with psoriasis create additional disease burden and decrease the quality of life.[3,32] Contrary to the present study, a study reported that the presence of another disease in patients with psoriasis did not affect internalized stigma.[15]

In the present study, 40.5% of the patients did not receive treatment regularly. These patients and those who visited the hospital for their treatment and symptoms had high levels of internalized stigma and low quality of life. In psoriasis, compliance with the treatment is low, and the internalized stigma level is high.[15] Patients with psoriasis are incompatible with treatment, unable to cope with symptoms, have a negative body image, and withdraw socially. In addition, patients who have no hope of recovery, cannot cope with the symptoms, and do not follow the treatment have a lower quality of life.[30]

Psychological problems are also common in patients with psoriasis, and these problems increase cigaret and alcohol consumption.[30] In the present study, 46.8% of the patients smoked, their internalized stigma level was higher, and their quality of life was lower than those who did not. Similarly, a study found that 43.2% of patients with psoriasis smoked, their internalized stigma level was high, and their quality of life was low.[15] Another study found a relationship between increased smoking and antidepressant use and low quality of life in patients with psoriasis.[33]

In the present study, as patients' age and disease duration increased, their internalized stigma levels increased, and their quality of life decreased. In patients with psoriasis, their internalized stigma level increases with an increasing duration of illness.[17] In contrast to this study, Alpsoy *et al*.[15] did not find a relationship between age and internalized stigmatization in patients with psoriasis. Patients with psoriasis at a young age, where physical appearance is important, experience higher levels of stigma than older patients.[5] The quality of life of young patients with psoriasis is lower, but as they get older, they become more experienced in managing the symptoms and more successful in dealing with these symptoms.[21] A study reported that as a recurrent disease, psoriasis causes patients to feel despair, fail to plan for the future, and a have decreased quality of life.[11] Healthcare professionals should provide necessary training and support for patients with psoriasis, which should focus on older patients with psoriasis and patients with chronic disease.

The most important limitation of the study is the absence of a control group. Data collection tools are limited to patients' self-reports. This study was limited to 222 patients with a diagnosis of psoriasis from a single center. Thus, the results may not be generalizable to the entire population with psoriasis.

CONCLUSIONS

Internalized stigmatization level was found to be high, and the quality of life was low in patients with psoriasis. In addition, as the internalized stigma level increased, the quality of life decreased. Moreover, sociodemographic characteristics, psychological, physical, and sexual health, and family, work, and social life affect the internalized stigma and quality of life of patients with psoriasis. Health professionals should provide significant support to patients by decreasing stigma and increasing the quality of life. Health professionals play an important role in preventing stigmatization by supporting patients with psoriasis psychologically and socially and informing society about psoriasis. Health professionals must make significant contributions to preventing psoriasis to worsen, ensuring that the individual is being active and functional, decreasing the psychological effects of the disease, and increasing the quality of life.

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CONFLICT OF INTEREST

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