

Neglected Victims of Psoriasis

Gözardı Edilmiş Psoriasis Mağdurları

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ABSTRACT Objective: The quality of life of patients is closely related to the quality of life of family members who share the same environment. The quality of life of the relatives may deteriorate more than the quality of life of patients. Except for atopic dermatitis, the impact of skin diseases on the families of patients has been largely neglected. In this study, we aimed to investigate how the quality of life of family members was affected by the psoriatic patients' disease. **Material and Methods:** Seventy psoriasis patients, their relatives and controls were included in the study. Psoriasis severity index (PASI), Nail Psoriasis Severity Index (NAPSI), Psoriasis Quality of life Questionnaire (PQLQ), Dermatological Diseases Family Impact Scale (DeFIS) and Hospital Anxiety and Depression Scale (HADS) were used to determine severity of the disease, and nail psoriasis, quality of life of the psoriatic patient, effect of the patient's psoriasis on the relatives' quality of life, anxiety and depression levels of the patients, respectively. **Results:** Of the relatives of psoriatic patients, 94.3% reported psychological problems, 57.1% reported financial burden, 61.4% reported problems with physical well-being, 51.4% had social and 81.4% had patient care need problems. The DeFIS scores of the relatives correlated with the PQLQ ($r=0.413$, $p=0.00$), HADS-depression ($r=0.277$, $p=0.02$) and NAPSI ($r=0.240$, $p=0.046$) scores of the patients. **Conclusion:** Our results suggest that psoriasis affects the quality of life of the patient, as well as the relatives. Family members should also be supported psychosocially for the patients' well being.

Keywords: Psoriasis; family members; quality of life; nail psoriasis severity index; psoriasis severity index; depression

ÖZET Amaç: Hastaların yaşam kalitesi, aynı ortamı paylaşan aile bireylerinin yaşam kalitesi ile yakından ilgilidir. Yakınların yaşam kalitesi, hastaların yaşam kalitelerinden daha fazla bozulabilir. Atopik dermatit dışında, deri hastalıklarının hastaların aileleri üzerindeki etkisi büyük ölçüde ihmal edilmiştir. Bu çalışmada aile bireylerinin yaşam kalitesinin psoriatik hastaların hastalığından nasıl etkilendiğini araştırmayı amaçladık. **Gereç ve Yöntemler:** Çalışmaya 70 psoriasis hastası, yakınları ve kontrolleri dahil edildi. Hastalığın şiddetini belirlemek için Psoriasis Şiddet İndeksi (PASI), Tırnak Psoriasis Şiddet İndeksi (NAPSI), Psoriasis Yaşam Kalitesi Anketi (PQLQ), Dermatolojik Hastalıklar Aile Etki Ölçeği (DeFIS) ve Hastane Anksiyete ve Depresyon Ölçeği (HADS) kullanılarak hastalık şiddeti, tırnak tutulumu, psoriatik hastanın yaşam kalitesi, hastanın sedef hastalığının yakınlarının yaşam kalitesi, hastaların anksiyete ve depresyon düzeylerine etkisi belirlendi. **Bulgular:** Psoriatik hasta yakınlarının %94,3'ü psikolojik sorunlar, %57,1'i maddi yük, %61,4'ü fiziksel sağlık sorunları, %51,4'ü sosyal ve %81,4'ü hasta bakım ihtiyacı sorunları bildirdi. Yakınlarının DeFIS puanları, hastaların PQLQ ($r=0,413$, $p=0,00$), HADS-depresyon ($r=0,277$, $p=0,02$) ve NAPSI ($r=0,240$, $p=0,046$) puanları ile korele idi. **Sonuç:** Sonuçlarımız sedef hastalığının hasta ve yakınlarının yaşam kalitesini etkilediğini düşündürmektedir. Hastaların iyiliği için aile üyeleri de psikososyal olarak desteklenmelidir.

Anahtar Kelimeler: Psoriasis; aile üyeleri; yaşam kalitesi; tırnak psoriasis şiddet indeksi; psoriasis şiddet indeksi; depresyon

Psoriasis is a chronic skin condition associated with psychological problems including anxiety and depression, negatively affecting the quality of life, self esteem and sexual life of the patients. Recent studies have shown that skin conditions may have adverse effects not only on the patients, but also on the quality

of life of the family members. However, the effect of skin disease such as psoriasis on the family of patients has been largely neglected in the clinics.¹⁻⁴

Since the quality of life of patients and that of their relatives/care-givers are closely related, it is important to determine which aspects of the relatives'

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lives are predominantly affected. The aim of this study was to identify the family impact of psoriasis and its relationship with the clinical parameters of the disease using tools such as Psoriasis Area Severity Index (PASI), Psoriasis Quality of Life Questionnaire (PQLQ), Nail Psoriasis Severity Index (NAPSI), Hospital Anxiety and Depression Scale (HADS) scores. To our knowledge, this is the first study from our country reporting the relationship between quality of life of psoriatic patients and their family members and also the first study in the literature evaluating the impact of nail involvement, depression and anxiety levels of the psoriatic patients on quality of life of family members.

MATERIAL AND METHODS

Seventy consecutive patients diagnosed by a dermatologist with plaque and guttate psoriasis for at least 6 months, and their relatives were included in this case-control study. The study protocol was approved by the Medical Ethics Committee of the Süleyman Demirel University Medical Faculty Research Hospital (02.03.2011,05) and informed consent form was obtained from all individuals. Presence of any systemic and dermatological disease other than psoriasis and age under 18 years were the exclusion criteria. Patients evaluated in the clinic were enrolled in the study according to the order of arrival, if they met the study criteria and agreed to participate in the study. The diagnosis of psoriasis was confirmed clinically and/or histopathologically. The severity of psoriatic lesions and nail psoriasis, the quality of life as well as anxiety and depression levels of the patients were assessed by using PASI, NAPSI, PQLQ and HADS, respectively. In addition, Dermatological Diseases Family Impact Scale (DeFIS) was used to assess the impact of psoriasis on family members/care-givers.

PASI: In this scoring system, the severity of erythema, scaling and infiltration of the lesions in areas including head, trunk and extremities are determined on a scale of zero to 72 points.⁵

PQLQ: The scale was developed by İnanır et al. to assess the effect of psoriasis on the quality of life of patients. It is a 17-item scale scored between 0-51. Higher scores correspond to poorer quality of life.⁶

NAPSI: This scale was developed by Rich et al. and is used to evaluate the severity of nail bed and nail matrix psoriasis on a scale 0-32.⁷

HADS: HADS is a commonly used measure of anxiety and depression levels of patients, developed by Zigmund et al. The cut-off score for depression and anxiety subscales is ≥ 8 .⁸

DeFIS: Turan et al. developed this scale to assess impact of dermatological disease on the quality of life of the families of patients.⁹ It is a 15-item scale, scored between 0-60. Higher scores correspond to poorer quality of life. The quality of life of the family members was determined in five different domains including psychological, financial, physical well being, care needs of the patient with skin disease and social disruption.

STATISTICAL ANALYSIS

Descriptive statistics were performed for all variables. All data collected were analyzed with SPSS software version 22 (Chicago, IL, USA). Normality of distribution was evaluated by Kolmogorov-Smirnov test. Quantitative variables were expressed as mean \pm standard deviation (SD) and median (min-max), qualitative variables were expressed as percentage or ratio. Data between two groups were compared by using independent t test and Mann-Whitney U test. Pearson's chi-square test was used for the analysis of qualitative variables. Relationship between different parameters was calculated by Pearson's correlation and analysis. Multiple linear regression analyses were used to assess independent associations between the DeFIS and PLQI and other variables. A p value < 0.05 was considered as statistically significant.

RESULTS

A total of 70 psoriasis patients, consisting of 36 males and 34 females, diagnosed for at least 6 months were enrolled in the study. Seventy relatives and 70 controls were also included in the study. Among the relatives of the patients examined in this study, 47 were spouses or partners, 12 were either the father or the mother (single patient's relatives), 8 were children and 3 were siblings. Sociodemographic and clinical

features of the patients, their family members and controls are shown in Table 1.

Aspects of the lives of family members that were affected as a result of the disease are shown in Table 2. Psychological impact was stated by 94.3% of the relatives while 57.1% of the relatives stated financial burden, 61.4% reported problems regarding physical well-being, 81.4% reported problems regarding care needs of the patient with skin disease, and 51.4% of the relatives indicated social disruption as a result of the patients' psoriasis (Table 2).

The mean DeFIS score of the relatives was 15.04±11.17 (0-42), whereas 2.07±2.58 (0-8) in controls. The difference was statistically significant. The mean values of PASI, PQLQ, NAPSI, HADS-depression and HADS-anxiety scores of the psoriasis patients are shown in Table 1. The anxiety level of 20 (28.6%) patients was above the cut off level of the HADS-anxiety scale, whereas the level of depression of 32 (45.7%) patients was above the cut off level of the HADS-depression scale.

The mean DeFIS and PQLQ scores were independent of the gender of the patients. DeFIS values of the relatives were positively and significantly correlated with the patients' PQLQ (r=0.413, p<0.001), HADS-depression (r=0.277, p=0.021) and NAPSI (r=0.240, p=0.046) scores. In addition, PQLQ scores of psoriasis patients were positively and significantly correlated with their PASI scores (r=0.286, r=0.016), HADS-anxiety score (r=0.455, p<0.001), HADS-depression score (r=0.310, p=0.009) and DeFIS scores of the relatives (r=0.413 p<0.000) (Table 3).

Multiple linear regression analyses indicated that the PQLQ scores of patients were significantly associated with their PASI and HADS-anxiety score as well as DeFIS scores of the relatives (Table 4). It was also observed that the most important predictor of DeFIS scores of the relatives was PQLQ of the patients (Table 4).

DISCUSSION

Psoriasis can negatively affect the quality of life and well-being of patients in many ways including men-

TABLE 1: Descriptive and clinical characteristics of cases and relatives.

	Cases (n=70)	Relatives (n=70)	Controls (n=70)	p ¹
Sex, M/F	36 /34	31/39	32/38	0.876 ²
Age, mean±sd (min-max)	40.92±16.22 (18-87)	41.92±11.94 (18-70)	38.98±11.21 (18-75)	0.142 ³
Duration of psoriasis, years, mean±sd (min-max)	12.73±10.64 (0.60-55)	-	-	
Age of onset of the disease, years, mean±sd (min-max)	28.24±15.17 (3-80)	-	-	
Type of psoriasis		-	-	
Plaque, n (%)	56 (80%)	-	-	
Guttate, n (%)	13 (18.57%)	-	-	
Palmoplantar, n (%)	1 (1.42%)	-	-	
Scalp, n (%)	35 (50%)	-	-	
Education level				
Primary school, n (%)	41 (58.6%)	39 (55.7%)	33 (47.1%)	0.198 ²
High School, n (%)	12 (17.1%)	20 (28.6%)	20 (28.6%)	
University, n (%)	17 (24.3%)	11 (15.7%)	17 (24.2%)	
PASI score, mean±SD (min-max)	6.25±6.36 (0.10-39.40)	-	-	
NAPSI score, mean±SD (min-max)	25.04±32.46 (0-160)	-	-	
DeFIS score, mean±SD (min-max)	-	12.5 (0-42)	2.5 (0-8)	<0.001 ⁴
PQLQ score, mean±SD (min-max)	15.52±9.22 (0-44)	-	-	
HADS-depression score, mean±SD (min-max)	7.17±3.95 (0-15)	-	-	
HADS-anxiety score, mean±SD (min-max)	8.31±4.18 (0-18)	-	-	

¹Relatives versus controls, ²Chi-square, ³Independent samples t-test, ⁴Mann-Whitney U test.

PASI: Psoriasis Area Severity Index; NAPSI: Nail Psoriasis Severity Index; DeFIS: Dermatological Diseases Family Impact Scale; PQLQ: Psoriasis Quality of life Questionnaire mean scores; HADS: Hospital Anxiety and Depression Scale; HADS-anxiety: Hospital Anxiety and Depression Scale-Anxiety; HADS-depression: Hospital Anxiety and Depression Scale-Depression.

TABLE 2: Aspects of family members' lives' affected.

	Number of subjects (%)
Psychological (94.3%)	
Feeling upset about patients skin disease	61 (87.1%)
Feeling worry, anxiety, fear about patients skin disease	56 (80%)
Feeling anger, tension about patients skin disease	35 (50%)
Feeling shame, helplessness, despair about patients skin disease	30 (42.9%)
Financial burden (57.1%)	
Increase in (hospital-doctor, medicines, cosmetics, specialized dresses) spendings about patients skin disease	40 (57.1%)
Physical well-being (61.4%)	
Suffering from fatigue, weakness, frazzle, frequently getting illness about patients skin disease	31 (44.3%)
Suffering from sleep disturbance (deterioration in sleep quality, morning fatigue due to deterioration in sleep quality, irregular sleeping) about patients skin disease	32 (45.7%)
Care needs of the patient about skin disease (81.4%)	
Increase in workload due to applying topical preparations, reminding medications and taking care of the patient	36 (51.4%)
Spend more time about the patient's care needs	29 (41.4%)
Needing more help and support about patients skin disease	39 (55.7%)
Social disruption (51.4%)	
Reduced or limited social life due to patients disease (Going to outside, visit friends, calling friends home, participation in various activities, holidays abroad decreased or stopped)	22 (31.4%)
Be exposed to negative behaviors from the surrounding people (attract attention, exposed to questions, explanation requirement, scoffing) about patients skin disease	24 (34.3)
Sexual relationship affected about patients skin disease	10 (14.3%)
Reduced attendance at leisure time activities (Hobbies, reading, going to the cinema) due to patients skin disease	22 (31.4%)
Trouble at home, school, business life (Can not go to work, can not concentrate on work, failure on duties, having problem with people at work, reduction in the number of hours in work)	17 (24.3%)

tal, physical, social and material. In our study PQLQ scores of patients were significantly associated with PASI scores indicating that psoriatic patients with severe lesions had more impaired quality of life consistent with previous studies.⁶⁻¹¹ Interestingly, it was suggested that subjective perception of disease severity might be the most important predictor of quality of life except for PASI in psoriasis.¹² Corroborating data in the literature, we found no significant differences in mean PQLQ scores between the sexes.¹¹⁻¹³

It is an inevitable reality that a patient's quality of life is closely related to the quality of life of caregivers and individuals who share the same environment.⁶ The lack of adequate psychosocial support of family members may negatively affect treatment success.⁹ In the current study, the quality of life of family members was significantly disturbed and was observed to be negatively affected by the psoriatic patient's disease in mainly five fields including psychological, financial, physical well-being, increased workload related to disease, and social life.

Psychiatric problems were reported in 98% of dermatology patients in a study.⁹ Psychological symptoms were described in family members especially during to flare-up episodes of the disease and also stated that family members worried about side effects of the drugs used and interpersonal relationships of the patients.¹⁴⁻¹⁶ It was reported that parents of children with psoriasis felt stress, felt concern regarding the child's condition and well-being, were sad, angry or frustrated especially due to exclusion of the children by their friends. Besides, some of the parents also reported that they used medications to aid mood recovery and to control their emotions.¹⁷ The same has been reported for other dermatologic conditions; thus, parents of children with atopic dermatitis and vitiligo have indicated significant psychological problems since they were the most important caregivers.^{18,19} In the current study, psychological problems were reported most frequently by family members who stated that they felt distressed, had worry-anxiety-fear, anger-tension, and

TABLE 3: Correlation coefficients between the variables.

	NAPSI (r value)	PQLQ (r value)	HADS-depression (r value)
DeFIS	0.240*(p:.046)	0.413**(p:.000)	0.277*(p:.02)
PASI	0.324**(p:.006)	0.286*(p:.016)	-
PQLQ	-	1	0.310**(p:.009)
HADS-anxiety	-	0.455**(p:.000)	0.548**(p:.000)
HADS-depression	-	0.310**(p:.009)	1

*p<0.05, **p<0.01.

TABLE 4: Multiple linear regression analyses associated with DeFIS and PQLQ in the 70 psoriasis patients.

Independent variables	Standart regression coefficients (β)	
	DeFIS	PQLQ
NAPSI	0.161	-
PQLQ	0.329**(p:.006)	-
HADS-depression	0.165	0.005
HADS-anxiety	-	0.413**(p:.001)
DeFIS	-	0.286**(p:.007)
PASI	-	0.274**(p:.007)
R ² (multiple coefficient of determination)	0.220**(p:.001)	0.386***(p:.000)

***p<0.001, ** p<0.01, *p<0.05.

shame-helplessness-despair about the patient’s disease. As the family experiences more disease-related problems, the occurrence of psychological problems among the family members is expected to increase.

Psoriasis has been reported to have strong associations with psychiatric disorders such as anxiety and depression.²⁰ In our study, it was detected that depression was an important parameter for the deterioration in quality of life of psoriatic patients as has been shown previously.²¹ In addition, we found that patients’ depression was an important parameter that significantly affected the quality of life not only of the patients, but also of family members. Although the risk of developing depression in patients was significantly correlated with the quality of life of both patients and relatives, it was independent from disease severity. Likewise, it was suggested that the state of psychological wellbeing of the parent and child was independent of disease severity in atopic dermatitis, another inflammatory dermatological condition.¹

Treatment modalities for psoriasis are expensive and time-consuming. Family members of psoriatic patients often face financial problems due to treatment expenditures, such as doctor’s fees and losing time from work.²¹ In our study, the relatives reported financial problems as a result of high expenditures in hospital appointments, examinations by doctors, medicines and special clothing. Moreover, relatives indicated absence from work, lack of concentration while at work, failure on duties, having interpersonal problems and reduction in the number of hours at work. In atopic dermatitis, it was noticed that special diets, extra laundry, bathing and special clothings brought extra spending costs for the families.¹⁸

The relatives also reported physical problems including fatigue, weakness, exhaustion, frequent illnesses and sleep disturbances in our study. In addition, the relatives suffered from morning fatigue due to deterioration of sleep quality. It was stated that relatives/care givers indicated sleep problems particularly during the exacerbation of psoriasis symptoms.¹⁵ In the current study, the vast majority of relatives with sleep disturbance were partners (81.25%) and the extent of sleep disturbance was reported as 38.6% by the partners, which was similar to the rate of sleep disturbance of psoriatic patients as reported in the literature (38.2%).²² Our result was not surprising, when considering that the patient’s sleep disturbance is highly likely to negatively affect the sleep quality of the partners. Also sleep disturbance rates were 52% and 64% in parents of psoriatic and atopic children, respectively, due to waking when the children woke up as a result of pain and itching or simply because of concerns about their child.^{17,23} Thus, sleep disturbance resulted in fatigue and difficulty in concentration of the parents who are primary care givers.

Relatives of patients with psoriasis who were also their primary caregivers were mostly concerned because of the nature of the disease and the need for topical treatments, which required their attention. It was reported that the treatment felt disgusting to them, and they spent a lot of time on treatment modalities, especially for topical applications.^{15,16,21} Majority of the relatives complained about extra housework, including extra laundry duties due to the

oily, greasy treatment and extra vacuuming due to scattered skin flakes. In our study, a majority of the relatives indicated patient care problems, including increase in workload of applying topical preparations and patient care duties, such as reminding the patients to administer their medications. We noticed that patient care highly time-consuming and most of the relatives stated the need for more help and support.

About half of the relatives examined in the current study reported disruption in their social lives. Relatives stated limitations in their social life such as going out, visiting or inviting friends, due to the patient's disease and the relatives reported an inability to carry out leisure time activities and hobbies. Time consuming and tiring care duties, especially topical treatment modalities are known to lead to social disruption in the relatives of psoriatic patients. Social disruption also resulted from embarrassment regarding the patient's condition with an inability to deal with incumbent questions regarding the patient's disease, lesions and flakes.^{15,17,21} In our study, relatives also had to deal with mobbing like behavior from the surrounding people (34.3%). They were exposed to questions, were required to provide explanations and faced deriding comments about the patient's skin disease. Relatives of patients with another dermatologic condition, vitiligo, have reported feelings of embarrassment as a result of similar events, which prompted them to isolate themselves from friends and/or community.²⁴

It is known that psoriasis has a negative impact on sexual life of the patients.¹ A deterioration of sexual life may stem from embarrassment due to impaired physical appearance and image of the patient in the bedroom, and the care duties of the patient.²⁵ In our study 14.3% of the family members reported that their sexual relationship was affected by the patient's disease. As psoriasis is known to cause sexual dysfunction, it was perhaps not surprising that a striking 90% of the family members who reported sexual dysfunction were partners of psoriatic patients.

The mean scores of quality of life of family members were independent of their gender. It may be related to the fact that these patients were adults. Thus, the gender of the caregiver was a significant factor in quality of life scores of family members of

children with dermatological diseases. The quality of life of the mother was reported to deteriorate more than that of the fathers as the vast majority of primary caregivers of children with these diseases was their mother.^{25,26}

Our findings suggest that there was a stronger correlation between the quality of life of the patient and his/her relative and that the most important predictor of DeFIS was PQLQ as in the literature.¹⁴ Although the family members' quality of life was significantly correlated with the quality of life of the patients, the PASI score was not correlated with the DeFIS scores. This indicates that the areas (psychological, material, physical well-being, physical maintenance and social life) in which the relatives were affected were more closely related to the quality of life of patients rather than the severity of the disease. Interestingly, we found that NAPSI scores were positively correlated with DeFIS, whereas PASI scores were not correlated with DeFIS. Thus, severity of nail involvement had a more important role in DeFIS than PASI. Also it may be considered that the appearance of the nail in patients with psoriasis was more important than the appearance of the skin in terms of relatives.

The major limitation of the study is that the DeFIS levels of other dermatological diseases could be included to compare with the data from psoriatic patients. The most powerful aspect of our study was the assessment of the impact of psoriasis on quality of life of the family, together with previously unscreened clinical parameters such as anxiety, depression and severity of nail involvement in psoriasis.

In conclusion, family members are the closest caregivers of psoriasis patients. Our results support that psoriasis affects not only the patients, but their relatives as well. A multidisciplinary approach is needed for high quality of life, with adequate support for psychological health of patients and their relatives for the successful management of the disease. New strategies to improve quality of life of family members as well as patients are essential.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct con-

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: İjlal Erturan; **Design:** İjlal Erturan; **Control/Supervision:** Pınar Yüksel Başak, Meltem Atay, Mehmet Yıldırım; **Data Collection and/or Processing:** İjlal Erturan, Gonca Meriç Biçici, Selma Korkmaz; **Analysis and/or Interpretation:** İjlal Erturan, Gonca Meriç Biçici, Havva Hilal Ayvaz; **Literature Review:** İjlal Erturan, Pınar Yüksel Başak, Meltem Atay; **Writing the Article:** İjlal Erturan, Havva Hilal Ayvaz; **Critical Review:** Pınar Yüksel Başak, Mehmet Yıldırım; **References and Fundings:** İjlal Erturan, Pınar Yüksel Başak, Gonca Meriç Biçici; **Materials:** İjlal Erturan.

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