



Estimating Quality of Life in Greek Patients with Hidradenitis Suppurativa

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Abstract

Background: Hidradenitis suppurativa (HS) is a chronic, relapsing skin disorder causing physical impairment and severe negative effects on patients' quality of life (QoL). The current study aims to estimate the impairment of QoL in HS and the role of disease advancement as a worsening factor.

Patients and Methods: Fifty patients and fifty healthy controls were sex and age matched and completed two questionnaires, the 'Dermatology Life Quality Index' (DLQI) and the 'SF-36v2™ Health Survey' (SF36). Comparisons were carried out between patients of different Hurley stage and between patients and controls' subgroups. The results of both questionnaires were correlated.

Results: According to Hurley system, 15 patients manifested first-stage HS, 13 second-stage HS, while 22 patients exhibited third-stage disease severity. HS patients experienced greater impact on their QoL compared to healthy controls (total mean DLQI score 13.10 ± 1.19 vs. 1.44 ± 0.32 , $p < 0.001$ and total mean SF36 score 53.13 ± 3.34 vs. 79.43 ± 1.38 , $p < 0.001$). Elevated score was attributed mainly to bodily pain and embarrassment due to skin disease. Patients with advanced stage of disease (Hurley III) obtained significantly higher score compared to patients with milder stage (Hurley I and II) in both questionnaires (mean DLQI score 18.55 ± 1.51 vs. 8.82 ± 1.3 , $p < 0.001$ and mean SF36 score 40.43 ± 4.44 vs. 70.26 ± 3.1 , $p < 0.001$, respectively). Total DLQI and SF36 scores were excellently correlated ($p < 0.01$, Spearman's correlation coefficient -0.771).

Conclusion: Patients with HS suffer a devastating impact on QoL. The phenomenon is greater within advanced disease stages.

Keywords: Hidradenitis suppurativa; Quality of life; Hurley stage; DLQI; SF36

Introduction

Hidradenitis suppurativa (HS) is a chronically recurrent skin disease. HS is characterized by the inflammation of the terminal hair follicle and affects predominantly apocrine gland-bearing regions [1]. HS incidence is estimated at 0.97%, according to the results of a large study conducted in France, while a Danish study estimated HS 1-year prevalence at 1% [2,3]. HS appears to be more common among females with a female/male ratio 3-5:1. The onset of the disease typically occurs after puberty [1].

HS clinical features include deep-seated nodules, polyporous comedones, draining sinuses, abscesses and scarring, while clinical presentation ranges from few, recalcitrant, suppurating lesions to severe, disabling disease. It is mainly localized at axillae, groins, gluteal regions and mammary folds, but also at genitalia, intragluteal region, perineum and scalp. Characteristic lesions, typical localization, chronicity and relapses establish the diagnosis of HS [4].

A well-established and universally accepted therapy does not exist. Current therapeutic options more usually administered to HS patients include antibiotics, retinoids, immunosuppressive treatment and surgery, while the number of studies conducted about the efficacy of biological agents against HS keeps rising [5].

The devastating nature of HS generated the need to provide a measurable way of the impact on the quality of life (QoL). The number of studies performed thus far about the assessment of QoL in HS patients is limited [6-10]. Von der Werth and Jemec measured the impairment of QoL in 114 patients with HS by using the Dermatology Life Quality Index (DLQI) [6]. Wolkenstein et al. evaluated the impact of HS on QoL by administering VQ-Dermato, Skindex-France and Short Form 36 (SF36) questionnaires at 61 patients [7]. In the study conducted by Matusiak et al. the effect of HS on psychological aspects of 52 patients was estimated by multiple questionnaires, including DLQI, Beck Depression Inventory-

Short Form (BDI-SF), Evers et al.'6-Item Scale', EQ-5D, Functional Assessment of Chronic Illness Therapy - Fatigue scale (FACIT-F) and Quality of Life Enjoyment and Satisfaction Questionnaire Short Form (Q-LES-Q-SF) [8]. Esmann and Jemec performed interviews at a total of 12 patients suffering from HS [9]. Onderdijk et al. assessed QoL and depression score in a cohort of 211 patients with HS by DLQI and Major Depression Inventory (MDI) questionnaires [10]. Experience of these studies revealed that HS causes a significant effect on QoL, greater than other dermatologic diseases [6-10].

A commonly asked question is whether these scores, and particularly DLQI, may be a helpful tool for the follow-up of the patients not only in clinical practice but also for patients' assessment in clinical trials. To this end, the current study is the first study, which aims to evaluate the impairment of QoL in HS patients in Greece not only using DLQI but also SF36. The need to introduce SF36 is based on its value on the assessment of physical and mental health.

Patients and Methods

The study was conducted from July 2010 to February 2011 at the outpatient clinic of Immunology of Infections at Attikon University General Hospital in partnership with the Public Health Department of National School of Public Health in Greece.

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The study was approved by the local ethics committee and written informed consent was provided by all studied individuals.

Patients were evaluated in the outpatient clinic and the diagnosis of HS was based on established clinical criteria [11]. For each patient, a brief report form about demographic characteristics, HS history and existence of co-morbidities was completed. Patients with any serious co-existing morbidity, which could affect their QoL and therefore the reliability of the results, were excluded. Finally fifty patients were included in the study and were separated into three groups according to Hurley staging system for HS [12].

Fifty healthy controls from other outpatient clinics of Attikon University General Hospital, who did not meet the criteria for HS, were sex and age matched with HS patients.

Permission for the usage of the Greek official language version of 'Dermatology Life Quality Index' (DLQI) was obtained by Professor Andrew Y. Finlay and for the 'SF-36v2™ Health Survey' (SF36) by Quality Metric Incorporated. Both patients and healthy controls were asked to fill out the questionnaires.

DLQI was the first dermatology-specific instrument to evaluate the impact of skin condition on QoL. It was created in 1994 by Finlay and Khan and it takes one to two minutes to complete. DLQI is a 10-item questionnaire summarized in six sections (symptoms and feelings, daily activities, leisure, work and school, personal relationships, treatment). Total score ranges between 0 and 30, while score for each question between 0 and 3. Higher score indicates greater impairment of QoL (0-1: no effect on QoL; 2-5: small effect; 6-10: moderate effect; 11-20: very large effect; and 21-30:extremely large effect).It is the most widely used tool in dermatology assessing QoL in the majority of relevant studies in patients with dermatologic diseases [13,14].

SF36 was developed by American scientists in health insurance survey. It is a generic instrument and it does not target a specific age group, disease or treatment. SF36 behaves well in a variety of clinical conditions and it is very useful in surveys of general and specific populations. It consists of 36 questions classified into 8 scales (physical function, role-physical, bodily pain, general health, role-emotional, social function, vitality, mental health). Each scale aggregates two to ten items and each item is used in scoring only one scale. The scales of SF36 are classified into two summary measures, physical component including physical function, role-physical, bodily pain and general health, and mental component including role-emotional, social function, vitality and mental health. Total score as well as single scale and item score ranges between 0 and 100. Lower score is considered indicative of greater effect on QoL. SF36 is completed in seven to ten minutes.It is the most studied tool in evaluating QoL and it is considered as the reference instrument by most researchers [14,15].

Results were presented by mean \pm standard deviation (SD). Statistical analysis was performed using the Mann-Whitney U test and Spearman's rank correlation coefficient. $P < 0.05$ was considered as statistically significant.

Results

A total of 50 patients (24 male and 26 female) aged 20-64 years (mean age 38.1 ± 12.4 years) were included in the study. The self-reported disease duration was assessed as from 1 to 35 years (mean disease duration 12.0 ± 8.1 years) and the mean age onset was 26.2 ± 11.0 years old ranging from 14 to 57 years old. According to Hurley system,15 patients (30%) manifested first-stage HS,13 patients (26%) second-stage HS and 22 (44%) exhibited third-stage disease severity.

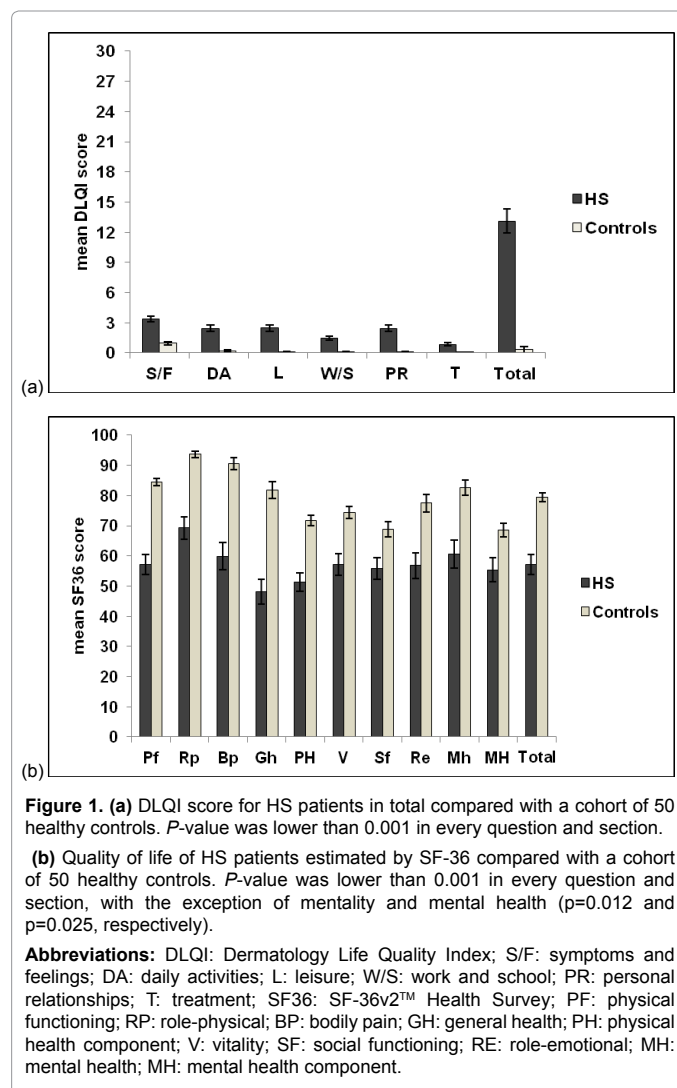


Figure 1. (a) DLQI score for HS patients in total compared with a cohort of 50 healthy controls. P -value was lower than 0.001 in every question and section.

(b) Quality of life of HS patients estimated by SF-36 compared with a cohort of 50 healthy controls. P -value was lower than 0.001 in every question and section, with the exception of mentality and mental health ($p=0.012$ and $p=0.025$, respectively).

Abbreviations: DLQI: Dermatology Life Quality Index; S/F: symptoms and feelings; DA: daily activities; L: leisure; W/S: work and school; PR: personal relationships; T: treatment; SF36: SF-36v2™ Health Survey; PF: physical functioning; RP: role-physical; BP: bodily pain; GH: general health; PH: physical health component; V: vitality; SF: social functioning; RE: role-emotional; MH: mental health; MH: mental health component.

DLQI and SF36 scores for HS patients and for healthy controls are shown in Figure.1. Patients demonstrated a total DLQI score of 13.10 ± 1.19 and a total SF36 score of 57.13 ± 3.34 indicating a very large impairment of QoL. P -value was lower than 0.001 in every question and section of both DLQI and SF36 with the exception of mentality and mental health of SF36 ($p=0.012$ and $p=0.025$, respectively) indicating that HS patients experienced greater impact on their QoL in comparison with healthy controls.

Total mean DLQI scores for each particular Hurley stage subgroup are shown in Table 1. HS had a moderate impact on QoL in Hurley I stage patients (total mean score 6.47 ± 1.88), while Hurley II and III patients experienced a very large impairment (total mean score 11.54 ± 1.52 and 18.55 ± 1.5 , respectively).The highest score was observed at second question about embarrassment and self-consciousness due to skin condition for all three subgroups.

Hurley stage III patients had significantly greater impact on QoL indicated by markedly elevated score in total mean DLQI and in each section compared with Hurley stage I alone and with Hurley stage I and II together with the exception of clothes selection ($p > 0.053$). Hurley stage I patients differed significantly from Hurley stage II patients in total DLQI score and in three sections including symptoms and

DLQI QUESTIONS AND SECTIONS	HURLEY I (n=15)	HURLEY II (n=13)	HURLEY III (n=22)	HURLEY I vs. II	HURLEY I vs. III	HURLEY II vs. III	HURLEY I, II vs. III
1. Symptoms and feelings	2.00 ± 0.47	3.38 ± 0.37	4.32 ± 0.30	p=0.024	p<0.001	p=0.081	p=0.001
1a. Soreness, pain	0.87 ± 0.26	1.54 ± 0.22	2.14 ± 0.17	p=0.051	p=0.001	p=0.044	p=0.001
1b. Embarrassment	1.13 ± 0.27	1.85 ± 0.19	2.18 ± 0.17	p=0.048	p=0.004	p=0.201	p=0.010
2. Daily activities	1.20 ± 0.44	2.31 ± 0.38	3.41 ± 0.41	p=0.033	p=0.001	p=0.097	p=0.003
2a. Shopping, housework	0.60 ± 0.29	0.69 ± 0.21	1.73 ± 0.25	p=0.343	p=0.007	p=0.010	p=0.001
2b. Clothes selection	0.60 ± 0.19	1.62 ± 0.24	1.68 ± 0.24	p=0.004	p=0.004	p=0.818	p=0.053
3. Leisure	1.00 ± 0.47	2.00 ± 0.34	3.77 ± 0.43	p=0.015	p<0.001	p=0.009	p<0.001
3a. Social and leisure activities	0.60 ± 0.25	1.00 ± 0.23	2.00 ± 0.25	p=0.141	p=0.001	p=0.009	p<0.001
3b. Sports	0.40 ± 0.24	1.00 ± 0.20	1.77 ± 0.24	p=0.014	p=0.001	p=0.032	p=0.001
4. Work and school	0.73 ± 0.28	1.31 ± 0.38	2.05 ± 0.23	p=0.289	p=0.001	p=0.091	p=0.003
5. Personal relationships	1.07 ± 0.47	1.92 ± 0.61	3.73 ± 0.41	p=0.191	p<0.001	p=0.019	p<0.001
5a. Partner, friends, relatives	0.53 ± 0.24	1.15 ± 0.32	1.73 ± 0.26	p=0.112	p=0.004	p=0.168	p=0.009
5b. Sexual difficulties	0.53 ± 0.24	0.77 ± 0.32	2.00 ± 0.23	p=0.666	p<0.001	p=0.006	p<0.001
6. Treatment	0.47 ± 0.19	0.62 ± 0.24	1.27 ± 0.26	p=0.596	p=0.040	p=0.132	p=0.029
Total score	6.47 ± 1.88	11.54 ± 1.52	18.55 ± 1.51	p=0.050	p<0.001	p=0.003	p<0.001

Abbreviations: DLQI: Dermatology Life Quality Index

Table 1: DLQI score (mean ± SD) for each particular Hurley stage group (Hurley I, Hurley II, Hurley III).

SF-36 SCALES AND DIMENSIONS	HURLEY I (n=15)	HURLEY II (n=13)	HURLEY III (n=22)	HURLEY I vs. II	HURLEY I vs. III	HURLEY II vs. III	HURLEY I, II vs. III
1. Physical health	75.10 ± 3.72	65.95 ± 4.71	39.66 ± 4.09	p=0.197	p<0.001	p=0.001	p<0.001
1a. Physical functioning	86.00 ± 3.02	83.85 ± 4.20	49.32 ± 5.25	p=0.814	p<0.001	p=0.002	p<0.001
1b. Role-physical	77.92 ± 6.39	75.48 ± 8.11	38.35 ± 5.60	p=0.852	p<0.001	p<0.001	p<0.001
1c. Bodily pain	69.83 ± 6.53	50.00 ± 7.19	32.16 ± 5.45	p=0.089	p<0.001	p=0.049	p=0.001
1d. General health	66.67 ± 4.09	54.49 ± 4.89	38.83 ± 4.24	p=0.101	p<0.001	p=0.026	p<0.001
2. Mental health	71.10 ± 5.20	68.00 ± 4.90	41.19 ± 5.13	p=0.662	p=0.001	p=0.003	p<0.001
2a. Vitality	66.67 ± 5.68	65.38 ± 4.78	42.90 ± 5.81	p=0.763	p=0.014	p=0.014	p=0.003
2b. Social functioning	74.17 ± 6.84	68.27 ± 5.77	38.07 ± 5.23	p=0.357	p<0.001	p=0.002	p<0.001
2c. Role-emotional	75.56 ± 6.38	77.56 ± 7.45	40.15 ± 6.62	p=0.830	p=0.001	p=0.002	p<0.001
2d. Mental health	68.00 ± 5.97	60.77 ± 6.48	43.64 ± 6.12	p=0.320	p=0.014	p=0.072	p=0.010
Total score	73.10 ± 4.33	66.98 ± 4.42	40.43 ± 4.44	p=0.259	p<0.001	p=0.001	p<0.001

Abbreviations: SF36: SF-36v2™ Health Survey

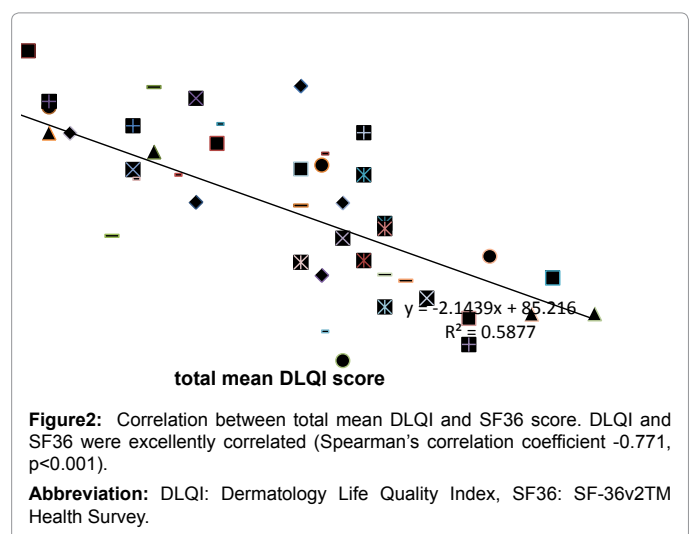
Table 2: SF-36 score (mean ± SD) for HS patients of different Hurley stage (Hurley I, Hurley II, Hurley III).

feelings, daily activities and leisure. Statistically significant differences were also found between Hurley stage II and III patients in total score, leisure and personal relationships.

The results of SF36 scores in each particular Hurley stage subgroup are presented in Table 2. Total mean SF36 score was assessed as 73.10 ± 4.33 for Hurley I patients, 66.98 ± 4.42 for patients exhibiting Hurley II disease severity and 40.43 ± 4.44 for patients manifesting a third-stage HS. Patients of first-stage HS demonstrated the lowest score at general health scale, while patients of second and third-stage HS at bodily pain scale.

The subgroup of Hurley III patients experienced greater impact on QoL at a statistically significant grade compared with the subgroup of Hurley I alone and to the subgroup of Hurley I and II patients together in SF36 as a total and in each scale. Hurley III patients differed significantly from Hurley stage II patients in total SF36 score and in each scale score with the exception of mental health. No statistically significant differences were seen between Hurley stage I and II patients.

Significant negative statistical correlations were depicted between total DLQI and SF36 scores (Spearman's correlation coefficient -0.771, p<0.001) [Figure 2]. DLQI correlated with physical and mental component of SF36 at a statistically significant grade (Spearman's correlation coefficient -0.740, p<0.001 and -0.752, p<0.001,



respectively).

Statistical analysis showed no significant relationship between a variety of factors, including gender, age, disease duration, age at onset, and the score at both questionnaires (p>0.05).

Discussion

The current study is the first study conducted in Greece about the estimation of QoL in patients with HS. The combination of DLQI and SF36 is used for the first time for evaluating QoL in HS patients. The findings reveal a very large impact on QoL of patients suffering from HS.

Total mean DLQI score is in agreement with previously published data from studies conducted in other countries, where it ranged from 8.4 ± 7.5 to 12.7 ± 7.7 [6,8,10,16,17]. Matusiak et al. recorded a total mean DLQI score of 5.77 ± 4.59 for Hurley I patients, 13.10 ± 6.41 for Hurley II and 20.40 ± 6.67 for Hurley III [8]. These results are comparable to our findings.

The second question of DLQI about embarrassment and self-consciousness due to skin condition obtained the highest mean score. In contrast to the results of the current study, von der Werth and Jemec demonstrated that the highest score was observed for the first question about pain, soreness, stinging or itching (mean 1.55 points) [6].

In comparison with the findings of Matusiak et al, both studies recorded that only disease intensity and not gender, age at onset or disease duration played significant role in deterioration of QoL [8]. Contrary to the results of the referred studies, von der Werth and Jemec pointed to a statistically significant relationship between early disease onset and DLQI score [6].

DLQI is the most broadly used questionnaire in dermatology offering the opportunity to compare the effect of several skin diseases on QoL [14]. When comparing DLQI scores obtained for the HS population of the present study with those obtained for other skin disorders, it is apparent that the scores for HS are far greater than those reported for melasma [18,19], acne [13,20,21], psoriasis [22-29], atopic dermatitis [22-24,30,31], vitiligo [13,32-36], alopecia [37], cutaneous lupus erythematosus [38], ichthyosis [39], urticaria [40,41], rosacea [24], contact dermatitis [42].

The importance of using the SF36 questionnaire comes from the potency for detecting the psychosocial impact of the disease whatever fails only with DLQI. This is consistent with the results of using SF36 in other dermatoses [21,43-48].

Wolkenstein et al. have been the only researchers, who used SF36 for assessing QoL in HS patients. With the exception of physical function dimension (mean score 71.3 ± 27.4), the current study demonstrated higher score at the rest of the scales. The lowest score was observed at the scale of vitality in comparison with the present study, where bodily pain was the most negatively influenced scale (mean score 40.4 ± 20.4 vs. 48.10 ± 4.2 , respectively). Both studies recorded lower scores in SF36 as the disease became more intense. Wolkenstein et al. demonstrated also that early disease onset and long disease duration deteriorated QoL. In the current study, no such relationship was found [7].

Determination of correlation between DLQI and SF36 in HS has not been reported previously. Strong correlations were found between DLQI and other questionnaires including Beck Depression Inventory-Short Form, EQ-5D, EQ-5D-VAS, Functional Assessment of Chronic Illness Therapy - Fatigue scale and Quality of Life Enjoyment and Satisfaction Questionnaire Short Form, with the exception of Evers et al. "6-Item Scale" [8].

As far as correlations between DLQI and SF36 are concerned, the majority of studies about QoL in other skin diseases found that the strongest correlations were between total DLQI and SF36 mental

health dimensions. This result could be attributed to the fact that skin diseases mainly affect psychosocial aspects of life [20,43]. However, in the current study, the correlation between total DLQI and SF36 mental health dimensions was as strong as the correlation between total DLQI and SF36 physical dimension. HS patients experience a great impairment of psychosocial aspects of life, but also severe pain and derangement of physical functioning due constant inflammation and location of the lesions [8,9].

DLQI is not only a simple measure for estimating life quality in skin diseases, but it also correlates positively with HS intensity and severity [6,8,14]. With regard to the reasons above, practitioners should be encouraged to use this instrument in everyday clinical practice and in therapeutic trials. The number of therapeutic trials using DLQI as an instrument for estimating patients' course is rising [49-52].

DLQI is focused mainly on patients' functioning. Emotion and mental health is not sufficiently evaluated [14]. This fact must be taken into consideration because of the psychosocial impact of HS. HS patients may suffer from depression, while high stigmatization level and low self-esteem promote isolation [8,9].

On the other hand, SF36 is considered as the instrument of choice for evaluating health-related life quality and it has been used in a wide spectrum of skin diseases. It estimates both physical and mental health and it correlates well with DLQI. The fact that the minimal clinically important difference in dermatology is not exactly known is included in SF36 limitations [14].

Both questionnaires highlighted disparities between Hurley stage I and III patients. DLQI scores reflected better the differences between Hurley stage I and II. Second-stage HS may cause greater impact on function rather than on mental condition compared to first-stage. SF36 was more effective in assessing differences between Hurley II and III patients. Patients suffering from third-stage HS may experience more severe impairment of mental health rather than of skin condition and function. It seems that a combination of DLQI and SF36 usage is more effective in the holistic approach of an HS patient. Bronsard et al. recommended a combination of DLQI and SF36 for evaluating QoL in plaque type psoriasis [53], whereas both et al. SF36 and Skindex-29 for the assessment of QoL in skin diseases [14].

Conclusions

HS is a dermatologic condition causing great impact on QoL. The severity stage of HS according to Hurley classification was found to be the only factor affecting the level of impairment at a statistically significant grade. The usage of both dermatology-specific and generic questionnaires measuring QoL is vital in everyday clinical practice and trials. It is recommended that questionnaires should be filled out at first contact with an HS patient and that their completion may be repeated after treatment. Patients experiencing a high level of impairment should be encouraged to seek psychological advice; formation of supporting groups may also be helpful [9]. The devastating impact on QoL points towards an intensive effort for research for an effective therapeutic method.

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