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ORIGINAL ARTICLE

Validity of EQ-5D-5L, Skindex-16, DLQI and DLQI-R in patients with hidradenitis suppurativa

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Abstract

Background Numerous generic, skin- and disease-specific health-related quality of life (HRQoL) measures are available for patients with hidradenitis suppurativa (HS). Yet, robust psychometric evidence is lacking in many aspects of these outcome measures.

Objectives We sought to determine convergent and known-groups validity of multiple generic and skin-specific HRQoL measures and to identify predictors of impaired HRQoL in patients with HS.

Methods Between 2017 and 2019, a multicentre cross-sectional study was carried out involving 200 consecutive HS patients. HRQoL outcomes included the EQ-5D-5L, EQ visual analogue scale (EQ VAS), Skindex-16, Dermatology Life Quality Index (DLQI) and DLQI-Relevant (DLQI-R). Disease severity was graded by HS-Physician's Global Assessment (HS-PGA) scale and the Modified Sartorius scale (MSS).

Results Overall, 77%, 56%, 51%, 46% and 28% reported problems in the pain/discomfort, usual activities, anxiety/depression, mobility and self-care dimensions of EQ-5D-5L. Mean ± SD EQ VAS, DLQI and DLQI-R scores were 64.29 ± 22.68, 11.75 ± 8.11 and 12.19 ± 8.33, respectively. Skindex-16 responses indicated that the emotional burden of HS (64.55 ± 29.28) far exceeded those of functioning (49.40 ± 34.70) and physical symptoms (46.74 ± 29.36). EQ-5D-5L, EQ VAS, DLQI, DLQI-R and Skindex-16 total scores had moderate or strong correlations with each other (range: |0.487| to |0.993|), weak or moderate correlations with HS-PGA (|0.350| to |0.433|) and weak correlations with MSS (|0.324| to |0.389|). DLQI-R slightly outperformed DLQI both in terms of convergent and known-groups validity. Being female, lower education level, more severe disease and genital involvement were associated with worse HRQoL ($P < 0.05$).

Conclusion This study provides high-quality evidence that among skin-specific outcomes, the DLQI, DLQI-R and Skindex-16, and among generic instruments, the EQ-5D-5L are suitable to be used in HS patients. In future research, we recommend the use of existing well-validated HRQoL tools instead of developing new measures for each study. The development of composite measures that combine physician- and patient-reported outcomes is not supported by evidence in HS.

[Correction added on 25 July 2020, after first online publication: in the Abstract section, the ± signs were missing and have been added to this version.]

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Conflicts of interest

None declared.

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Introduction

Hidradenitis suppurativa (HS), also known as acne inversa, is a chronic inflammatory disease of the skin, characterized by recurrent abscesses, nodules, fistulas and scarring in the apocrine gland-bearing regions.[1–3] Lesions predominantly affect the axillary, inguinal, submammary and perianal areas. The prevalence has been estimated to be between 0.03% and 1% in Europe.[4–6] HS most commonly occurs in the third and fourth decades of life, and women are affected two to three times as frequently as men.[7,8] Clinical manifestations may range from mild localized lesions to severe deep-seated, inflamed lesions in multiple body regions.[2] HS can be associated with substantial pain, malodorous discharge and decreased range of motion that contribute to a dramatic decrease in the health-related quality of life (HRQoL).[9,10]

Currently, there is a lack of consensus regarding the HRQoL instruments to be used in clinical practice or trials with HS patients.[10–12] Recently, we have witnessed an intensive development of new HS-specific HRQoL instruments specifically targeting clinical trials and consultations [e.g. HS Quality of Life (HiSQOL and HS-QoL) and HIDRAdisk].[13–16] Nevertheless, clinical trials and observational studies need results on multiple HRQoL measures, including disease-specific, skin-specific and generic instruments, to precisely evaluate health status of patients and response to treatments, to ensure comparability across studies and to provide input data for economic evaluations of treatments.

Among skin-specific HRQoL measures, the Dermatology Life Quality Index (DLQI) is the most commonly used tool in HS patients.[17,18] In addition to the DLQI, potential candidates for brief and easy-to-administer skin-specific outcomes to be used in HS patients are DLQI-Relevant (DLQI-R) or Skindex-16.[19,20] DLQI-R is a new scoring modification developed for the DLQI that improved the convergent validity, responsiveness and discriminatory power of the questionnaire in psoriasis patients,[19,21–23] but has not yet been tested in HS. Validation of Skindex-16 is also currently incomplete in this patient population.[24] Among generic HRQoL tools, the EQ-5D is one of the most widely used questionnaires that demonstrated good validity and responsiveness in patients with chronic skin diseases, such as psoriasis, atopic dermatitis and pemphigus.[25–28] Clinical data collected with the EQ-5D can also be used when assessing cost-effectiveness of health interventions. It has two versions suitable for adults, the EQ-5D-3L and the newer EQ-5D-5L.[29,30] While the EQ-5D-3L proved to be a useful and valid measure in HS patients,[31–35] the EQ-5D-5L was not previously validated in HS.

The objective of this study is to evaluate HRQoL in HS patients using multiple instruments (DLQI, DLQI-R, Skindex-16 and EQ-5D-5L) and to determine the convergent validity, known-groups validity and floor or ceiling effects of these tools. We also aim to explore which socio-demographic and clinical characteristics are associated with worse HRQoL outcomes in HS.

Methods

Study design and patient population

Between September 2017 and October 2019, a cross-sectional questionnaire survey was carried out at three academic dermatology clinics in Hungary. Permission for conducting the study was granted by the Scientific and Ethical Committee of the Medical Research Council under reference no. 40579-2/2017/EKU. Consecutive patients aged 18 years and above diagnosed with HS were recruited to the study. A written informed consent was obtained from each participant prior to the data collection.

The questionnaire consisted of two sections. In the first section, patients were asked about socio-demographic characteristics, general health status and HRQoL. We measured general HRQoL by using the EQ-5D-5L and EQ visual analogue scale (EQ VAS).[29,30,36] The Hungarian EQ-5D-5L value set was applied to generate index scores.[37] For capturing skin-specific HRQoL, we used the Dermatology Life Quality Index (DLQI),[38] DLQI-Relevant (DLQI-R)[19] and Skindex-16[20] (Appendix S1, Supporting Information). Patients were asked to assess their severity using the Patient's Global Assessment (PtGA) VAS providing a range of scores from 0 ('not severe at all') to 100 ('very severe'). In the second section, dermatologists provided information about medical history, comorbidities, disease characteristics, disease severity and treatments applied. Disease severity was evaluated by the following measures: HS-Physician Global Assessment (HS-PGA)[39] and Modified Sartorius Score (MSS) by Sartorius et al. (2009).[40]

Statistical analyses

We report socio-demographic and clinical characteristics as proportions for categorical variables, and means with SDs and medians with interquartile ranges for continuous variables. For all outcome measures, missing items were handled according to the developer's instructions. Floor or ceiling effects for the outcome measures, expressed as the proportion of the patient population in the worst and best possible health states, were considered to be present if >15% of patients achieved the lowest or highest possible score, respectively.[41] Convergent validity between the outcome measures was tested by Spearman's rank-order correlations [very weak: rho (r_s) < 0.20, weak: 0.20–0.39, moderate: 0.40-0.60 and strong: 0.60<]. A strong correlation was expected between DLQI, DLQI-R and Skindex-16 and a moderate correlation between these three and the EQ-5D-5L index and EQ VAS.[34] The non-parametric Kruskal–Wallis H-test was used to compare HRQoL outcome scores in subgroups of patients based on disease severity as measured by HS-PGA.[32,42] It was

hypothesized that patients with more severe disease had worse HRQoL.[32,34,42–48] The effect size (ES, η^2) and relative efficiency (RE) statistics were also estimated. The ES, indicating the percentage of variance in the dependent variable explained by the independent variable, was calculated according to the following formula:

$$\eta^2(H) = \frac{\text{Kruskal} - \text{Wallis } H - k + 1}{n - k}$$

where n denotes the sample size, and k is the number of groups. ES values were considered as small if ≥0.01, moderate if ≥0.06 and large if ≥0.14.[49] The RE was computed as the ratio of the ESs of two HRQoL outcomes, where the test statistic of the DLQI was used as a reference. A RE > 1 indicated that the HRQoL outcome of interest was more efficient in discriminating between known groups compared to the DLQI.

We performed multiple linear regression analyses to evaluate how key socio-demographic and clinical variables influenced HRQoL outcomes. Variables in the final model were selected with a backward elimination approach. The presence of heteroscedasticity was examined using the Breusch–Pagan test and corrected using robust standard errors. For all the statistical tests, a two-sided P-value < 0.05 was considered statistically significant. All statistical analyses were performed with SPSS 25.0 (IBM, Armonk, NY, USA) and Stata 14 (StataCorp LP., College Station, TX, USA).

Results

Patient characteristics

Overall, 200 adult patients with HS were included in this study. Mean ± SD age was 37.13 ± 12.43 years, and 123 (61.5%) were male (Table 1). A total of 81.2% of the patients were overweight or obese (BMI > 25), and 70.5% were smokers. The mean disease duration was 4.76 ± 6.72 years. The most common localizations of disease were axillary (77.5%), inguinal (63.5%) and gluteal (29.5%). Comorbidities were present in 92 (46.0%) patients, the most common of which were hypertension (14.0%), acne vulgaris (7.0%), Crohn's disease (6.0%), diabetes (6.0%) and psychiatric illnesses (6.0%).

Table 1 Demographic and clinical characteristics of patients with HS

Variables	Mean (SD) or *N* (%)
Age (years)	37.13 (12.43)
Sex	
Female	77 (38.5%)
Male	123 (61.5%)
Education (missing *n* = 1)	
Primary	40 (20.1%)
Secondary	129 (64.8%)
Tertiary	30 (15.1%)
Body mass index (BMI) – kg/m^2 (missing *n* = 3)	
Underweight (<18.5)	2 (1.0%)
Normal (18.5–24.9)	35 (17.8%)
Overweight (25.0–29.9)	68 (34.5%)
Obese (≥30)	92 (46.7%)
Smoking	
Smoker	141 (70.5%)
Ex-smoker	35 (17.5%)
Non-smoker	24 (12.0%)
Family history of HS (missing *n* = 2)	37 (18.6%)
Comorbidities	92 (46.0%)
Disease duration (years)	4.76 (6.72)
HS-PGA (missing *n* = 7)	
Clear	6 (3.1%)
Minimal	7 (3.6%)
Mild	37 (19.3%)
Moderate	69 (35.9%)
Severe	40 (20.7%)
Very severe	34 (17.7%)
Body region affected	
Axillary	155 (77.5%)
Inguinal	127 (63.5%)
Gluteal	59 (29.5%)
Genital	52 (26.0%)
Perianal	22 (11.0%)
Submammary	24 (12.0%)
Other	12 (6.0%)
Current treatment	
None	37 (18.5%)
Topical therapy (only)	59 (29.5%)
Systemic non-biological	77 (38.5%)
Biological	27 (13.5%)
Surgical therapy in the past 12 months	65 (32.5%)

HS, hidradenitis suppurativa; HS-PGA, Physicians' Global Assessment of HS severity.

Disease severity and health-related quality of life scores

Mean ± SD scores for HS-PGA were 3.20 ± 1.22, for MSS 60.69 ± 50.24 and for PtGA VAS 69.62 ± 22.22 (Table 2). The mean DLQI and DLQI-R scores were 11.75 ± 8.11 and 12.19 ± 8.33, with the most problems reported regarding sore, itchy or painful skin (87.4%), embarrassment (81.0%), clothing (74.2%) and social activities (67.7%) (Appendix S2, Supporting Information). Forty (20.7%) patients marked at least one 'not relevant' response on the DLQI. Among the Skindex-16 subscales, the highest mean scores occurred in the emotions subscale (64.55 ± 29.28), followed by functioning (49.40 ± 34.70) and symptoms (46.74 ± 29.36), respectively. In the emotions subscale, patients were most bothered by worrying about their condition (e.g. that it will spread, get worse, scar, be unpredictable) and the persistence/recurrence of their skin condition

Table 2 Disease severity and HRQoL scores of HS patients

Outcome measures	*N*	Mean (SD)	Median (IQR)	Floor effect *N* (%)	Ceiling effect *N* (%)
EQ-5D-5L (−0.848 to 1)	198	0.76 (0.21)	0.86 (0.71–0.96)	0 (0%)	29 (14.6%)
EQ VAS (0–100)	198	64.29 (22.68)	70.00 (50.00–80.00)	0 (0%)	4 (2.0%)
DLQI (0–30)	198	11.75 (8.11)	11.00 (5.00–18.00)	10 (5.1%)	1 (0.5%)
DLQI-R (0–30)	198	12.19 (8.33)	11.00 (5.42–19.00)	10 (5.1%)	2 (1.0%)
Skindex-16 total score (0–100)	198	53.56 (28.11)	54.66 (33.04–76.65)	4 (2.0%)	6 (3.0%)
Symptoms (4 items)	198	46.74 (29.36)	50.00 (20.83–66.67)	14 (7.1%)	10 (5.1%)
Emotions (7 items)	198	64.55 (29.28)	71.43 (42.86–90.48)	5 (2.5%)	25 (12.6%)
Functioning (5 items)	198	49.40 (34.70)	46.67 (15.83–83.33)	21 (10.6%)	21 (10.6%)
PtGA VAS (0–100)	199	69.62 (22.22)	70.00 (50.00–90.00)	0 (0%)	36 (18.1%)
HS-PGA (0–5)	193	3.20 (1.22)	3.00 (2.00–4.00)	6 (3.1%)	34 (17.6%)
Modified Sartorius Score†	198	60.69 (50.24)	48.00 (22.00–84.25)	1 (0.5%)	n/a

For EQ-5D-5L and EQ VAS, higher scores refer to better health status, and for all other measures, higher scores represent worse health status.
DLQI, Dermatology Life Quality Index; n/a, not applicable; PGA, Physicians' Global Assessment of disease severity; PtGA VAS, Patient's Global Assessment of disease severity visual analogue scale; VAS, visual analogue scale.
†The measure has no upper limit.

(Appendix S3, Supporting Information). Overall, 77.4%, 56.1%, 50.7%, 46.2% and 28.3% of the patients with HS reported problems in the pain/discomfort, usual activities, anxiety/depression, mobility and self-care dimensions of the EQ-5D-5L descriptive system (Appendix S4, Supporting Information). The mean EQ-5D-5L index and EQ VAS scores were 0.76 ± 0.21 and 64.29 ± 22.68, respectively.

Ceiling or floor effects

The proportions of HS patients with the lowest and highest values for the DLQI (5.1% and 0.5%), DLQI-R (5.1% and 1.0%), Skindex-16 symptoms subscale (7.1% or 5.1%), Skindex-16 emotions subscale (2.5% and 12.6%), Skindex-16 functioning subscale (10.6% and 10.6%), Skindex-16 total score (2.0% and 3.0%) and EQ VAS (2.0% and 0%) were well below 15%, indicating no floor or ceiling effects. We found the EQ-5D-5L index scores slightly skewed towards the highest value (14.6%). No floor effects were found for the EQ-5D-5L.

Convergent validity

Regarding convergent validity, the DLQI, DLQI-R, Skindex-16 total score and EQ-5D-5L index score had strong correlations with each other (range of r_s = |0.650| to |0.993|) and moderate correlations with EQ VAS and PtGA VAS (range of r_s = |0.434| to |0.592|) (Table 3). HS-PGA correlated moderately with DLQI (r_s = 0.418) and DLQI-R (r_s = 0.433), and weakly with any other HRQoL measure (range of r_s=|0.311| to |0.390|). The MSS exhibited weak correlations with all HRQoL outcomes (range of r_s = |0.280| to |0.389|). All correlation coefficients were proved to be statistically significant.

Table 3 Spearman's correlations between outcome measures

Variables	EQ VAS	DLQI	DLQI-R	Skindex-16 total score	Skindex-16 symptoms	Skindex-16 emotions	Skindex-16 functioning	PtGA VAS	HS-PGA	MSS†
EQ-5D-5L (−0.848 to 1)	0.592	−0.697	−0.707	−0.650	−0.573	−0.500	−0.674	−0.434	−0.350	−0.334
EQ VAS (0–100)	–	−0.512	−0.519	−0.487	−0.454	−0.359	−0.493	−0.408	−0.358	−0.370
DLQI (0–30)	–	–	0.993	0.859	0.750	0.725	0.847	0.542	0.418	0.376
DLQI-R (0–30)	–	–	-	0.867	0.756	0.732	0.856	0.546	0.433	0.389
Skindex-16 (0–100)	–	–	–	–	0.869	0.900	0.932	0.513	0.390	0.365
Skindex-16 Symptoms (0–100)	–	–	–	–	–	0.675	0.713	0.417	0.364	0.331
Skindex-16 Emotions (0–100)	–	–	–	–	–	–	0.791	0.453	0.311	0.280
Skindex-16 Functioning (0–100)	–	–	–	–	–	–	–	0.521	0.385	0.360
PtGA VAS (0–100)	–	–	–	–	–	–	–	–	0.327	0.383
HS-PGA (0–5)	–	–	–	–	–	–	–	–	–	0.873

All coefficients are statistically significant ($P < 0.05$). For EQ-5D-5L and EQ VAS, higher scores refer to better health status, and for all other measures, higher scores represent worse health status.
DLQI, Dermatology Life Quality Index; DLQI-R, DLQI-Relevant; HS-PGA, Physicians' Global Assessment of HS severity; MSS, Modified Sartorius Score; PtGA VAS, Patient's Global Assessment of disease severity visual analogue scale; VAS, visual analogue scale
†There is no theoretical maximum.

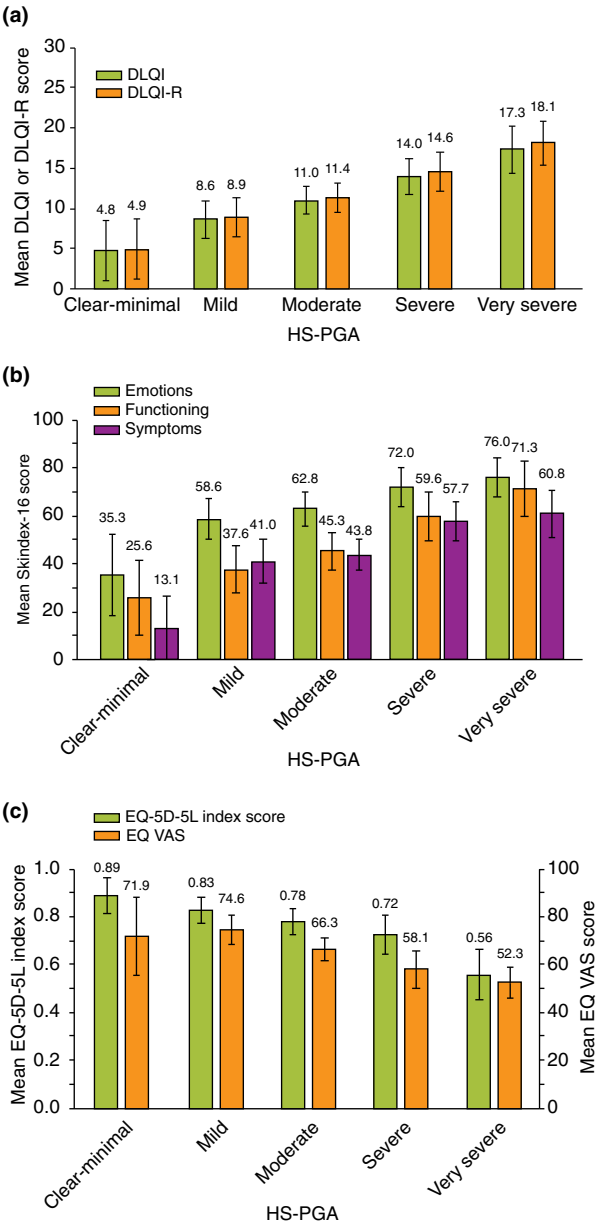

Figure 1 Known-groups validity of HRQoL measures in HS. ES, effect size; HS-PGA, Physicians' Global Assessment of HS severity; RE, relative efficiency. (a) DLQI and DLQI-R. DLQI: *P*-value < 0.001, ES: 0.163. DLQI-R: *P*-value < 0.001, ES: 0.176, RE: 1.076. (b) Skindex-16. Emotions subscale: *P*-value < 0.001, ES: 0.090, RE: 0.555. Functioning subscale: *P*-value < 0.001, ES: 0.134, RE: 0.819. Symptoms subscale: *P*-value < 0.001, ES: 0.146, RE: 0.894. (c) EQ-5D-5L index and EQ VAS. EQ-5D-5L: *P*-value < 0.001, ES: 0.116, RE: 0.709. EQ VAS: *P*-value < 0.001, ES: 0.111, RE: 0.683.

Known-groups validity

More severe disease measured by HS-PGA was associated with worse HRQoL scores using all outcome measures ($P < 0.001$) (Fig. 1a–c). The differences between severity groups were significant with moderate to large effect size for all HRQoL measures (0.090–0.176). Relative efficiency of the HRQoL measures with reference to the DLQI varied noticeably: the DLQI-R (1.076) outperformed, while the Skindex-16 (emotions 0.555, functioning 0.819, symptoms 0.894), EQ-5D-5L (0.709) and EQ VAS (0.683) lagged behind the DLQI in differentiating between severity groups.

Predictors of HRQoL in HS

In multivariate regression analyses, female patients experienced a greater impairment in HRQoL on the DLQI, DLQI-R and Skindex-16 compared to their male peers (Table 4). Patients who had a higher level of education had substantially better HRQoL scores on any outcome measure. Higher disease severity (as measured by the HS-PGA) resulted in worse HRQoL in all instruments except EQ VAS. In all outcomes with the exception of EQ-5D-5L, genital involvement was associated with a large negative impact on HRQoL. These variables explained a total of 9.2% (EQ VAS) to 28.8% (Skindex-16) of the variance in HRQoL ($P < 0.001$).

Discussion

The present study provides extensive validation data about DLQI, DLQI-R, Skindex-16 and EQ-5D-5L in patients with HS. To our knowledge, we are the first to validate the EQ-5D-5L questionnaire and the DLQI-R scoring in this patient population. In general, all HRQoL measures demonstrated a good convergent and known-groups validity for severity and no floor or ceiling effects.

The DLQI, Skindex-16 and EQ-5D-5L scores from this study are consistent with those reported in earlier studies. The mean DLQI score of the patients (11.75) was within the range of means from previous studies (8.31–12.67).[10] Up to now, one study[24] reported mean Skindex-16 scores in 140 Italian HS patients (62.5) that were somewhat higher than our results (mean 53.56). So far, the EQ-5D-5L has been used in one study involving 150 HS patients in Ireland.[50] A higher proportion of Irish patients reported anxiety/depression on the EQ-5D-5L (71.5%) in comparison with our results in Hungary (51.3%). The proportion of Irish patients reporting problems on the other four dimensions of the EQ-5D-5L descriptive system, index scores or EQ VAS scores are not available from this study.[50] In our study, female sex, lower education level, genital involvement and more severe disease were associated with more impaired HRQoL. Prior research using various instruments indicated that patients with worse HRQoL scores included elderly,[32,42] females,[40,48] smokers[35,40] and patients with higher BMI,[35,40] comorbidities,[42] inguinal localization[42] and higher disease severity.[32,34,42–48]

Our findings highlight that the emotional burden of HS far exceeds the burden caused by its physical symptoms. The, at

Table 4 Multivariate linear regression of HRQoL outcomes

	DLQI			DLQI-R			Skindex-16			EQ-5D-5L index			EQ VAS		
	β	SE*	*P*-value	β	SE*	*P*-value	β	SE	*P*-value	β	SE*	*P*-value	β	SE	*P*-value
Constant	6.06	2.19	0.006	6.42	2.24	0.005	30.38	8.24	<0.001	0.767	0.092	<0.001	61.70	3.82	<0.001
Sex															
Male	Ref.			Ref.			Ref.								
Female	3.21	2.90	0.004	3.43	1.13	0.003	13.64	3.69	<0.001						
Education															
Primary	Ref.			Ref.			Ref.			Ref.			Ref.		
Secondary	−2.26	1.36	0.100	−2.1	1.39	0.063	−9.37	4.63	0.044	0.117	0.052	0.025	5.94	4.040	0.143
Tertiary	−5.07	1.67	0.003	−5.11	1.78	0.005	−19.27	6.32	0.003	0.200	0.072	0.006	13.36	5.410	0.014
HS-PGA															
Clear minimal	Ref.			Ref.			Ref.			Ref.					
Mild	2.44	2.01	0.227	2.53	2.03	0.216	15.09	7.99	0.060	−0.017	0.090	0.849			
Moderate	5.35	1.91	0.006	5.51	1.96	0.005	22.10	7.49	0.004	−0.086	0.085	0.312			
Severe	7.94	1.96	<0.001	8.41	2.01	<0.001	33.47	7.82	<0.001	−0.152	0.089	0.087			
Very severe	9.83	2.31	<0.001	10.5	2.3	<0.001	35.05	8.32	<0.001	−0.294	0.094	0.002			
Genital localization															
No	Ref.			Ref.			Ref.						Ref.		
Yes	3.80	1.36	0.006	3.60	1.36	0.009	11.69	4.27	0.007				−10.91	3.46	0.002
R^2, *F*-test *P*-value	0.275, $P < 0.001$			0.282, $P < 0.001$			0.288, $P < 0.001$			0.165, $P < 0.001$			0.092, $P < 0.001$		

HRQoL, health-related quality of life; HS-PGA, Physicians' Global Assessment of HS severity
*Robust standard errors.

most, moderate correlations found between HRQoL and disease severity further confirm this observation. Previous studies also reported weak-to-moderate correlations between HRQoL outcomes and disease severity in HS.40,42-44 These results may provide an explanation why the development of composite measures aiming to combine HRQoL outcomes with objective symptoms assessed by the physician was unsuccessful in HS.[51,52] For example, the development of International Hidradenitis Suppurativa Severity Score System (IHS4) was completed without the inclusion of any patient-reported outcome measure, as the authors found the DLQI to limit the performance of this new scoring system.[51]

Being a generic instrument, the EQ-5D-5L may offer several specific advantages over disease- or skin-specific questionnaires. First of all, it allows comparisons across health conditions (both within and outside of dermatology) and with general population reference values.[36] To illustrate this, the distribution of responses on the EQ-5D-5L from this study may be compared to those from patients with psoriasis and pemphigus vulgaris obtained in two previous cross-sectional surveys by our research group in Hungary.[27,28] Figure 2 demonstrates that patients with HS had a greater impairment in HRQoL than reported in psoriasis or pemphigus vulgaris in all five dimensions except for mobility. The difference between HS and the other two dermatologic conditions was particularly large for the pain/discomfort dimension. Furthermore, the EQ-5D-5L index scores can be used to calculate health utility scores to estimate quality-adjusted life years (QALYs) in cost-effectiveness analyses of health interventions. Since the first biological drug, adalimumab, was approved for HS by both the U.S. Food and Drug Administration and the European Medicines Agency in 2015, there has been a growing interest in demonstrating the economic value of heath gains associated with new costly treatments.[53]

The DLQI-R performed slightly better in terms of both convergent and known-groups validity in comparison with the DLQI. However, as DLQI-R scores differ from DLQI scores only in patients who responded 'not relevant'[54–57] to one or more items, the net improvement may be considerably higher in this subset of patients. A growing body of literature suggests that in research settings, the DLQI-R is able to more precisely reflect the HRQoL impact of skin disease compared to the DLQI.[19,21–23] For example, the DLQI-R improved convergent validity, responsiveness and discriminatory power of the questionnaire in patients with psoriasis.[19,21,23] It has also been confirmed that the DLQI score bands are applicable to the DLQI-R scoring.[22] Nonetheless, this improvement in measurement properties comes at an expense: the calculation of DLQI-R scores requires a slightly more complex formula that may deter clinicians from using it during consultations. To encourage its routine use, a DLQI-R scoring chart has been developed.[21] In the future, an electronic scoring may help to reduce the burden on clinicians and researchers.

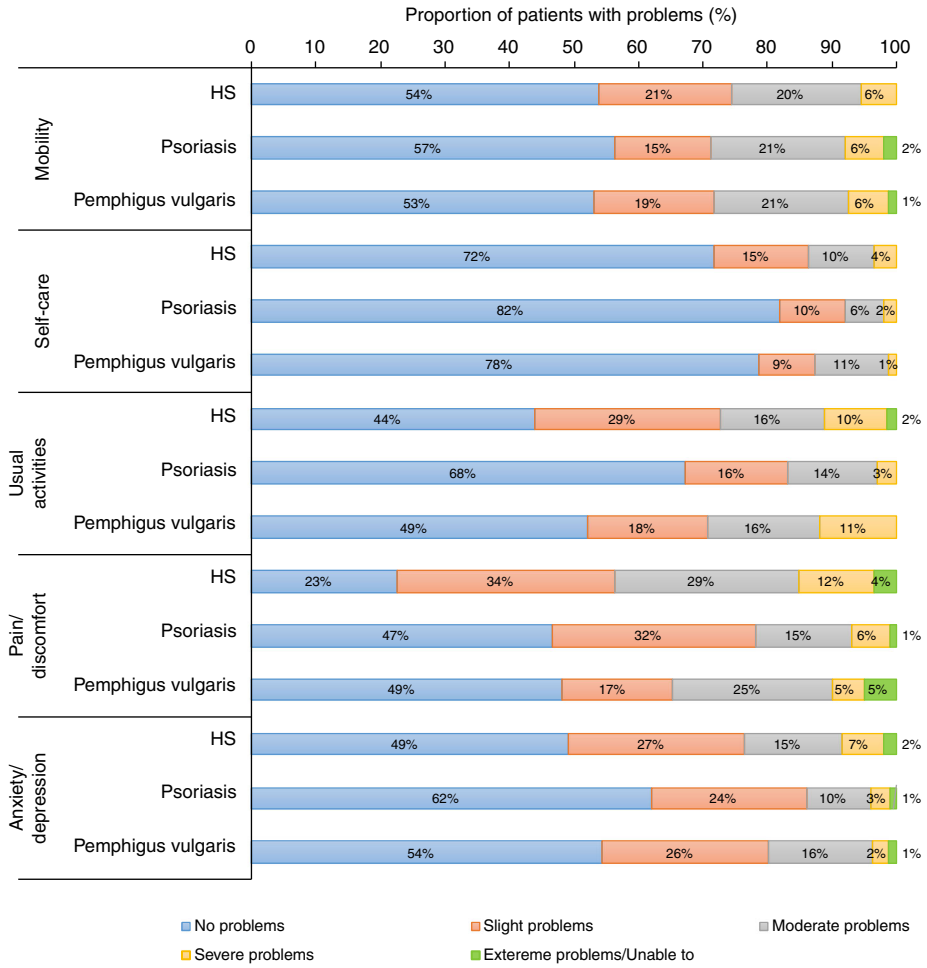

Figure 2 Problems reported on the five EQ-5D-5L dimensions in patients with HS compared to psoriasis and pemphigus vulgaris. HS, hidradenitis suppurativa. Psoriasis: $n = 238$, mean age 47.4 ± 15.2 years, mean Psoriasis Area and Severity Index 8.7 ± 9.2, biological therapy 36.6% (Hungary). 27 Pemphigus vulgaris: $n = 81$, mean age 55.9 ± 13.5, mean Autoimmune Bullous Skin Disorder Intensity Score 13.4 ± 18.1, biological therapy 0% (Hungary).[28]

This study has several strengths, including the use of a reasonably large sample of HS patients and a good representation across demographic and clinical subgroups. Furthermore, the large number of HRQoL measures used in the study allowed detailed analyses of the relationships between existing tools in this patient population. The following limitations should be noted. Firstly, we did not compare measurement properties of the EQ-5D-5L against other generic HRQoL instruments, such as the SF-36. Secondly, responsiveness and test–retest reliability could not been tested here because of the cross-sectional nature of our study.

Numerous generic, skin-specific and disease-specific HRQoL measures are available for patients with HS. Yet, the majority have been employed in just one or very few studies and robust psychometric evidence is lacking in many aspects of these outcome measures. This study contributed to fill in this gap by providing high-quality evidence that among skin-specific outcomes, the DLQI, DLQI-R and Skindex-16, and among generic instruments, the EQ-5D-5L are suitable to be used in HS patients. In future research, we recommend the use of existing well-validated HRQoL tools instead of developing new measures for each study.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Outcome measures used in the study
Appendix S2. Distribution of responses for DLQI items
Appendix S3. Distribution of responses for Skindex-16 items
Appendix S4. Distribution of responses for EQ-5D-5L items